



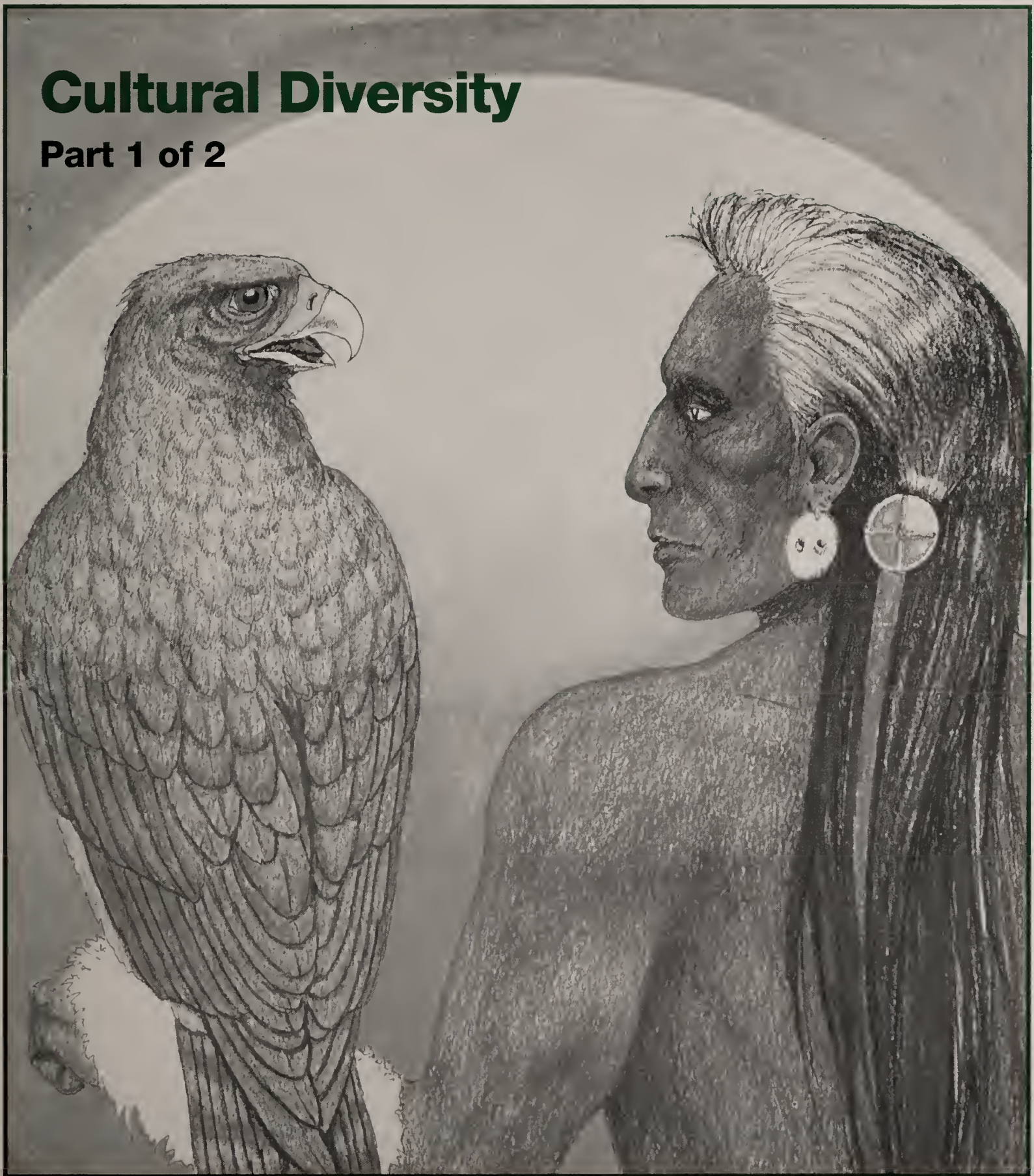
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AMERICAN Spring 1996 REHABILITATION

Cultural Diversity

Part 1 of 2



RSA's Capacity Building Project

The Rehabilitation Services Administration (RSA) has initiated its Capacity Building Project with the awarding of grants through a cooperative agreement to 17 educational institutions and nonprofit service agencies. The Capacity Building Project is one of the major components of the Cultural Diversity Initiative which grew out of the implementation of Section 21 of the 1992 amendments to the Rehabilitation Act of 1973.

Section 21, which is entitled, "Traditionally Underserved Populations," charges RSA with the responsibility for developing interventions which will increase the number of minority professionals working within the public rehabilitation program. One of the strategies called for in the legislation is to build the capacity of minority educational institutions, minority owned businesses, and organizations serving individuals with disabilities from minority population groups to successfully compete for and manage RSA, National Institute on Disability and Rehabilitation Research (NIDRR), and other federal grants, contracts, and cooperative agreements. This effort is intended to increase minority participation in the field, thus leading to better service delivery and higher quality outcomes for minority individuals with disabilities.

RSA's Project Officer for this effort is Ellen Chesley, who will be working with Dan Hopkins of Dan Hopkins & Associates to provide the management and oversight for the project. Mr. Hopkins will serve as the national coordinator and will be involved in the project's day-to-day operation. Mr. Hopkins previously served on the faculty of the Region VI Regional Rehabilitation Continuing Education Program (RRCEP) at the University of Arkansas. He was coordinator of the Rehabilitation Cultural Diversity Initiative for that region and has a long and distinguished record in the areas of cultural diversity, community development, program planning, proposal development, management, and leadership. He will work with Ms. Chesley and the directors of each of the funded projects to ensure that a strong and well coordinated national effort is planned and implemented. The directors of each project



Fredric K. Schroeder, Commissioner, RSA

will meet with officials from RSA, NIDRR, and the Office of Special Education (OSEP) to design an implementation plan for this 3-year project. This plan will guide the Capacity Building Project as it attempts to reach the widest possible audience. It strives to improve the opportunities for interested parties to acquire rehabilitation funding and build the capacity of the public rehabilitation program through the increased participation of minority professionals and improved service delivery to all individuals with disabilities.

The projects which are funded under the Capacity Building Project umbrella represent a broad cross section of organizational activity and expertise. The grantees are:

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Judith E. Heumann, Assistant Secretary
REHABILITATION SERVICES ADMINISTRATION
Fredric K. Schroeder, Commissioner
Frank Romano, Editor

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Asian Pacific Americans and Section 21 of the Rehabilitation Act Amendments of 1992

The Rehabilitation Cultural Diversity Initiative includes Asian Pacific Americans as a target group, yet little is known about the incidence and prevalence of disability among Asian Pacific Americans and, thus, little is known about their rehabilitation needs. This article provides a brief overview of the many groups which have been included under the rubric of Asian Pacific American. In addition, it attempts to dispel some myths, provide some insight into their culture and values, and offer a few suggestions related to their involvement in the vocational rehabilitation program.

Paul Leung, Ph.D.

The reauthorization of the Rehabilitation Act included what has become commonly known as Section 21. Essentially, Section 21 mandates outreach and inclusion of persons from minority ethnic groups into the state-federal vocational rehabilitation (VR) program and was due in part to congressional findings as well as other data suggesting differential participation of minority ethnic populations in the VR program (Ross & Biggi, 1986; Dziekan & Okocha, 1993; GAO, 1993). Bobbie Atkins, Ph.D., coordinator of a consortium of Rehabilitation Continuing Education Programs (RCEP's) working on Section 21 efforts, describes the goals of Section 21 as to "provide and enhance equal access to quality services and outcomes within the public rehabilitation programs for individuals representing cultural diversity" and to "expand career development for individuals in rehabilitation representing cultural diversity." Dr. Atkins points out that the target groups "include Afro-Americans, Hispanic Americans, Native Americans, Asian Americans, and Pacific Islanders" (1994).

Why are Asian Pacific Americans Included?

"Asian Pacific Americans" were included in the language of the amendments although specific rationale for their inclusion was not provided. In part, this is because very little data have been available regarding disability within the Asian Pacific American population. Current estimates probably do not accurately reflect the reality of disability incidence or prevalence among

the Asian Pacific population (Yang, et al., 1994). While prevailing opinion and evidence seem to suggest lower incidence and prevalence (McNeil, 1994) of disabilities among the Asian Pacific American population, the fact that disabilities are linked to poverty status and occupation would also suggest that some Asian Pacific American ethnic groups, because of their higher rates of poverty and representation in service occupations, may have higher incidence and prevalence rates than the majority population.

These variances can be traced in part to the fact that the category, "Asian Pacific Islander," was an artificial classification put into effect by Office of Management and Budget Statistical Directive 15 in 1977 (Wright, 1994). In reality, there is no one group or person that is Asian Pacific American, as opposed to Korean American, Samoan American, or Vietnamese American, which have their basis with a particular country or nation of origin. Because of the many ethnic groups categorized as Asian Pacific under Directive 15 and the usual practice of lumping all of them into an aggregate category, significant differences may be masked. These include differences not only related to each of the particular ethnic groups but to differences related to how long an individual has been in the United States, as well as other acculturation variables.

Who are Asian Pacific Americans?

Asian Pacific Americans are the fastest growing population in the United States today, with the primary growth of the last decade due to immigration. From approximately 1.5 per-

cent of the U.S. population in 1980, the Asian Pacific American population grew to comprise almost 3 percent in 1990, for a growth rate of more than 100 percent. While the majority of Asian Pacific Americans live in the five states of California, Hawaii, New York, Illinois, and Texas, Asian Pacific Americans are found in all areas of the country and are projected to increase to more than 10 percent of the total U.S. population by 2050. This is particularly important for the VR program, as Asian Pacific Americans will become increasingly a part of the clientele for the state-federal VR system.

Why is so Little Known About Asian Pacific Americans?

There are probably many reasons why there is limited understanding of Asian Pacific populations and the incidence and prevalence of disability among them. This overview will not provide a comprehensive coverage; hopefully, readers will look further for other resources and information.

One of the principal reasons for the limited information has been the perpetuation of the model minority myth that Asian Pacific Americans have no problems because they have literally made it in American society and, therefore, have no need for services. Time and again, media coverage has often called attention to characteristics such as income levels and educational achievement without full explanation of what those characteristics represent. The historical reliance on support systems internal to their ethnic community forced upon them as a result of anti-Asian sentiments has also given rise to the feeling that there is no need for services by external providers. Finally, disability has not been a priority concern with many Asian Pacific families adhering to cultural and religious values that view the occurrence of disability to be a reflection of their own failure and shame.

Asian Pacific Americans may have similar physical characteristics, such as dark hair and golden pigmentation of the skin, but come from groups sepa-

Table 1	
Asian	Pacific Islander
Chinese	Hawaiian
Filipino	Samoa
Japanese	Guamanian
Asian Indian	Carolinian
Korean	Fijian
Vietnamese	Kosraean
Cambodian	Melanesian
Hmong	Micronesian
Laotian	Northern Mariana Islander
Thai	Palauan
Bangladeshi	Papa New Guinean
Bhutanese	Ponapean (Pohnpeian)
Borneo	Polynesian
Celebesian	Solomon Islander
Ceram	Tahitian
Indochinese	Tarawa Islander
Indonesian	Tongan
IwoJiman	Trukese (Chuukese)
Javanese	Yapese
Malayan	
Maldivian	
Nepali	
Okinawan	
Pakistani	
Sikkim	
Singaporean	
Sri Lankan	
Sumatran	

rated by differences in history, customs, values, and religion. Composed of many distinct groups (Table 1) and differing experiences in the United States, the aggregate categorization may not only distort but present a perspective that is false. It is important to reiterate that there is no one monolithic group nor is there any one characteristic that can be described as Asian Pacific American.

There are major differences among these various groups and their history in the United States along with why their initial migration occurred. Some of the ethnic groups under the general rubric of Asian Pacific American have a history of antagonism and war with

each other and some countries in Asia continue to have acrimonious relationships with each other. In the United States, it has only been since the 1970's that individuals from the different ethnic groups within the Asian Pacific American community, recognizing the power of numbers, have begun to work together in pan-Asian ways.

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Recent immigrants may be of refugee status, bringing along the baggage of having spent time in holding locations with poor health and existing disability. These may be coupled with the stress of relocation and lack of a support system. Refugees who were involved with agricultural pursuits in their native country have difficulty transferring their skills in the United States (Ying, 1994). On the other hand, there are those groups that may be three to four generations away from when their great grandparents immigrated and who may have achieved success in education and occupation. Another ethnic group considered to be part of the Asian Pacific American rubric is the Asian Indian and other peoples from South Asia, with their widely disparate history and immigration experience. Also lumped into the Asian Pacific category are people from the Pacific islands who have another different history and culture. Add to these the Native Hawaiians who mirror the experiences of Native Americans in having their sovereignty removed and it is not difficult to see the complexity of the Asian Pacific American categorization.

Why are Asian Pacific Americans a Misunderstood Group?

For the most part, Asian Pacific Americans have been silent in voicing their needs in public and have relied on their internal communities to deal with their forced isolation from the larger majority. Chinatowns and Japanese and Korea towns arose as attempts to deal with community issues following anti-Asian activity by the majority society. Asian Pacific Americans are also misunderstood because of some of the achievements of segments of their population. The inability of many of the majority to "tell us apart" only adds to the thinking that "we are all alike." For example, there is the sometimes prevailing myth that Asian Pacific Americans do not experience discrimination. History, of course, provides a different perspective. As the only ethnic population to be specifically excluded by federal legislation and to be incarcerated during wartime, Asian Pacific

Americans continue to experience discrimination as they become inextricably linked to Asia because of their physical characteristics. Several notable violent acts against Asian Pacific Americans were perpetrated ostensibly because of this and because they were perceived as foreigners taking what the perpetrators considered to be American jobs.

Communication styles have also contributed to misunderstanding between Asian Pacific Americans and others. Strong emotional confrontations are not generally as well accepted with Asian cultures and the desire is to keep things on an even keel. Respect for those who are older and who are in positions of authority may keep an individual with disability from disclosing all that may be helpful to a rehabilitation professional. That the individual is seen as only a part of the larger familial structure may limit disclosure of difficulties within the family. Not only does this bring about misunderstanding, but also a feeling that the individual or family does not desire any help or assistance.

Have Asian Pacific Americans Made it?

One of the primary indicators often used to demonstrate the "success" of Asian Pacific Americans has been their household incomes, which have been consistently higher than other minority populations and in certain instances exceed even the majority population. However, Ong and Hee (1994) argue that it "is impossible to distill the economic status of Asian Pacific Americans into a single statistic." Ong and Hee further suggest that even with very high educational achievements, the average income of Asian Pacific Americans remains below that of the majority non-Hispanic white population. Further, "For every Asian Pacific American household with an annual income of \$75,000 or more there is roughly another with an annual income below \$10,000." In addition, higher average household income is often a reflection of larger numbers of the family being earners rather than higher per capita income.

... one reason for the higher average household income is the emphasis placed on education by Asian Pacific Americans . . .

Unquestionably, one reason for the higher average household income is the emphasis placed on education by Asian Pacific Americans and their concomitant educational achievements. The 1990 census reported that 37 percent of all Asian Pacific Americans 25 years of age and over had at least a bachelor's degree in contrast to 22 percent for non-Hispanic whites. It is also important to note that in spite of the high educational attainment of some Asian Pacific Americans, their salaries are not always commensurate with that educational attainment. For example, the average Asian Pacific American male who works full time, year round, earns about 10 percent less than white males, and for the West the difference is 12 percent (Hong & Hee, 1994). At the other extreme, there is a significant proportion (23 percent) of the Asian Pacific American population without a high school education, compared with 21 percent of non-Hispanic whites in this category.

Some of the available data suggest that the incidence and prevalence of disability may be much higher than current estimates. Disability is known to be related to occupation, education, and income. Some Asian Pacific groups are known to be more likely to be involved in service occupations and have lower than average income as well as lower earnings. The economic picture for Asian Pacific Americans may be

counter to conventional wisdom, and one must look beyond what seems to be apparent at first glance.

The available data only provides a brief glimpse of what may be the reality—a reality that may be poorly represented by existing data. The most obvious is the poor representation of Asian Pacific Americans resulting from aggregate reporting (Yu, 1993). Yang, Leung, Wang, and Shim (1994) suggest that a more in-depth examination of rehabilitation data is necessary if a real understanding of disability is to occur for the Asian Pacific population. Disaggregating data points to differences not readily apparent when only the aggregate category is reported.

What About Asian Pacific Americans and the Rehabilitation Process?

Asian Pacific Americans may avoid programs because they do not feel comfortable in them, are not aware of them, or because these programs have not been culturally appropriate. Especially for new immigrants who use English as a second language or whose cultural practices are foreign to mainstream counselors, vocational rehabilitation may be a difficult step to take. When family support systems, values, and religion are ignored, potential benefits are not apparent and the individuals and/or their families may be unwilling to follow through. The traditional U.S. emphasis on independence and self-sufficiency, while not necessarily in opposition to an Asian approach, may need detailed description and explanation. Expectations may not be similar to those espoused by the VR program. And in situations where Asian Pacific Americans have been openly discriminated against, the fear of working with strangers is very real.

As rehabilitation counselors may have discouraged persons with disabilities from seeking to enter certain occupations, based upon stereotyped ideas of what persons with specific disabilities can do, so also may Asian Pacific American participants with dis-

abilities often be persuaded that certain choices may be more suitable. Computer and math proficiency and occupations requiring less English and people skills may be encouraged rather than the choice of work which may be of interest to the individual. Rehabilitation counselors working with culturally different consumers must be willing to set aside some of their own beliefs and stereotypes to allow for true choice and decision making.

Attention to Asian values—but within the context of American society—may be important. Asian Pacific Americans even of second or third generations have been influenced to some extent by the beliefs and values of their parents, no matter how acculturated they may have become. Their values and their identities represent a combination and mixture which are no longer fully Asian. Adoption of American value systems does not mean that their Asian background is not important. The influences of expectations of family and self continue to have major impact. Personality that fits stereotypic perceptions, such as being quiet or unobtrusive, may be reinforced by the majority; in fact, behaviors which do not fit are discouraged and are seen by the majority as threatening and aberrant.

The role of families and the interdependence which is a hallmark of Asian culture and . . . suggests a strength not often found in an individualistic oriented society.

What are Asian Pacific American Attitudes Towards Disabilities?


While attitudes towards disabilities differ and vary greatly among individuals and cultures and are not always reflective of their country of origin, Asian

Pacific Americans generally have less favorable attitudes toward disability than the majority population and some other ethnic minority populations. For example, the Chinese word or character for disability implies that a person is useless and crippled. This is hardly a positive perception. Even Asian Pacific Americans several generations removed from initial immigration continue to be influenced by these negative attitudes. Paris (1993) found that ethnicity is related to attitudes toward people with disabilities. She found that Asians generally had the least positive attitudes, even when healthcare professionals are the subjects of the research (Paris, 1993). The influence of long-held beliefs continue to have impact on Asian Pacific Americans.

Because of the often interpreted perception that disability exists because of what one did in a previous life and that it may bring about shame to the family, families with members who have disabilities may attempt to keep them in the background and not call attention to their different needs. Given the emphasis on trying to succeed, many immigrant families do not want to place themselves in jeopardy by identification of different or unique needs. Individuals with disabilities may not be seen as positive, but the bonds of family remain as a source of support. The role of families and the interdependence which is a hallmark of Asian culture and, by extension, Asian Pacific Americans, suggests a strength not often found in an individualistic oriented society.

Summary

Section 21 promises to bring about a new era of responsiveness within the VR system to the unique needs of the many ethnic populations. Attention to cultural influence on understanding of disability and rehabilitation will bring innovative models that take into account the profusion of influences on the individual with disability and his/her family who are from minority ethnic populations. The response of vocational rehabilitation will come from the needs of the individual and no longer

from stereotypes and limited information. The final outcome will be that all Americans with disabilities will be better served. 

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Census Bureau Reports Large Increase in Number of Asian, Pacific Islander, American Indian, and Alaska Native Businesses

The number of businesses owned by Asians, Pacific Islanders, American Indians, and Alaska Natives in the United States increased 61 percent from 439,271 in 1987 to 705,672 in 1992, according to a report released recently by the Commerce Department's Census Bureau. This compares to a rate increase of 26 percent for all U.S. firms, from 13.7 million in 1987 to 17.3 million in 1992.

According to *The 1992 Survey of Minority-Owned Business Enterprises—Asians and Pacific Islanders, American Indians, and Alaska Natives* (MB92-3), receipts for these minority-owned businesses increased by 159 percent during this 5-year span, from \$40 billion to \$104 billion. In comparison, receipts for all U.S. firms grew 67 percent, from \$2.0 to \$3.3 trillion.

The number of businesses owned by Asians and Pacific Islanders increased 56 percent over this 5-year period from 386,291 to 603,439, while receipts increased 163 percent from \$36.5 to \$96.0 billion.

The number of American Indian- and Alaska Native-owned businesses increased 93 percent from 52,980 in 1987 to 102,234 in 1992. Receipts for these businesses increased by 115 percent from \$3.7 to \$8.1 billion.

Due to sampling methodology, detailed estimates are not available for all the minority-owned firms in the survey. Therefore, the following statistics cover 606,438 of the total number (705,672) of businesses reported in the survey.

Receipts per firm averaged \$165,000 for firms owned by members of these four minority groups, compared with \$193,000 for all U.S. firms. Thirty-five percent or 212,928 of these minority-owned businesses had receipts under \$10,000, while 12,517 of these firms had sales of \$1.0 million or more.

The survey also shows that the 22 percent (136,000 firms) of Asian-, Pacific Islander-, American Indian-, and Alaska Native-owned firms with paid employees accounted for 81 percent of gross receipts of these minority-owned firms. Of these firms, 705 had 100 or more employees and accounted for \$17.9 billion in receipts.

The service industries accounted for 45 percent of the businesses owned by Asians, Pacific Islanders, American Indians, and Alaska Natives but only 26 percent of gross receipts. The retail trade industry accounted for the next largest concentration of these minority-owned firms at 22 percent of the firms and 29 percent of the receipts.

Approximately 83 percent of these firms were sole proprietorships in 1992. Partnerships and subchapter S corporations comprised 8 and 9 percent, respectively. (A sole proprietorship is an unincorporated business owned by an individual; a partnership is an unincorporated business owned by two or more persons; and a subchapter S corporation is an unincorporated business with 35 or fewer shareholders.)

Three states—California, New York, and Texas—accounted for 55 percent of the firms owned by Asians, Pacific Islanders, American Indians, and Alaska Natives.

Hawaii had the highest percentage of firms owned by members of these minority groups at 49 percent; 44 percent of the receipts in the state were from these minority-owned businesses. California ranked second with 10 percent of all firms and 9 percent of all receipts. Alaska was third with 7 percent of all firms and 5 percent of all receipts.

Providing Outreach and Rehabilitation Counseling Services to Non-English Speaking Persons

Andrew M. O'Brien,
MS, CRC
Gary W. Rhoades, JD

The Congressional findings concerning the programs authorized in Titles II through VIII of the Rehabilitation Act stated that "Patterns of inequitable treatment of minorities have been documented in all major junctures of the vocational rehabilitation process." The minority populations discussed in Section 21, entitled "Traditionally Underserved Populations," include Latinos, African Americans, Asian Americans, and Native Americans with disabilities. The inequitable treatment had been suspected for a long time, even as the rate of increase for these racial, ethnic, and cultural minorities was 10 times higher than for white Americans. The findings confirmed that vocational rehabilitation (VR) provides these minorities with less training than their white counterparts and that VR consistently spent less money on minorities.

One reason for the discrepancy, especially in the Latino or Asian-Americans with disabilities populations, is that often the client's primary language is one other than English. Outreach and counseling become considerably more difficult—more difficult, but not impossible—when aimed at non-English speaking individuals with disabilities. A bilingual staff, which the majority of rehabilitation agencies or office staffs fail to offer, goes a long way toward

making outreach and vocational rehabilitation counseling meaningful for non-English speaking individuals with disabilities.

This article is offering the Congressional findings as a catalyst for vocational rehabilitation programs to step up their efforts in reaching out to and serving non-English speaking individuals with disabilities. This article shows how to design or improve outreach programs and then provide vocational counseling to a non-English speaking person with a disability.

Outreach

While the importance of having a bilingual staff is discussed below, it is equally important, and often a first step, that outreach efforts make the fact of the bilingual staff well known. Agencies and programs often cannot afford to duplicate posters, brochures, and business cards in other languages. When the money is tight and the program is providing those English materials, a simple proviso in at least one other language stating that the staff has bilingual capability (i.e., *Se Habla Español*) is easy and effective. Also, one should think about the liberal use of pho-

tographs and other graphics in posters and brochures where the text is mostly in English. Pictures are worth many words in any language.

When a program does develop materials in other languages, the staff should take care to assure that those materials are placed effectively and with cultural sensitivity. Cultural community centers and English as a second language classes are among the places where outreach would be high. The staff should also stay in contact with those community service groups that regularly see non-English speaking clients. In Sacramento, California, rehabilitation staff members are often bumping into one another at the city's monthly Hispanic Resource Luncheon, where any organization can report on its services and progress to the other groups and also pass out literature in English and Spanish.

Along with expense problems, in California and many other states, VR outreach programs are being abolished or cut back simply because the field offices are already overwhelmed with consumers. This occurs while the pop-

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ulation of people with disabilities continues to grow and, indeed, a 1993 U.S. General Accounting Office (GAO) report stated that only a small fraction of people who are potentially eligible for services are actually served.

However, given the Congressional findings, many programs should be responsible for increasing efforts to reach out to the traditionally underserved populations. These efforts include:

- using public service announcements on the Spanish and Asian Language radio and television stations,
- holding scheduled orientation sessions in other languages, and
- making public presentations in other languages.

Any vocational rehabilitation agency or program that is serious about improving services to non-English-speaking clients must begin with an organized outreach plan that encompasses all or more of the above suggestions. The plan should not be placed solely on the shoulders of one person—for example, the bilingual

staff member—but should be a cohesive teamwork effort to which all staff members are committed.

Upon determination that an individual's primary language is non-English, the entire focus of the rehabilitation counselor's assessment is altered.

Counseling

The traditional role of the VR counselor is to help persons with disabilities maximize their personal and vocational potential. In order to make an effective assessment of an individual's capacity to live independently and work

competitively, the counselor must evaluate the individual's condition as a whole. Certainly, the person's language skills and the specific language he/she speaks (or cannot speak) are parts of that condition, and, arguably, they are threshold issues to deal with in a rehabilitation context.

The types of information and/or issues which are most commonly important when assessing future work behavior and worklife are age, education (academic, vocational, on-the-job training, military service), marital status, financial status, transportation, military service, transferable skills, work experience, past promotional patterns, wage and salary information, nature of injury, residual functional capacities, emotional status, participation in vocational rehabilitation, and motivation (desire to work, willingness to move). Obviously, collecting this data and accurately assessing an individual's potential to benefit from vocational rehabilitation becomes much more difficult when that person does not speak English.

Upon determination that an individual's primary language is non-English, the entire focus of the rehabilitation counselor's assessment is altered. The counselor's efforts shift to the identification of available and appropriate resources. Absent resources which facilitate an evaluation of cognitive abilities, aptitudes, and interests, the counselor must rely more heavily upon techniques such as in-depth interviewing, transferable skills analysis, and client-initiated vocational exploration. Some of the most significant barriers faced by non-English speaking individuals with disabilities in California include:

- the absence of interpreter services,
- limited availability of vocational testing instruments in languages other than English,
- cultural insensitivity,
- insufficient bilingual work evaluation staff, and
- the absence of bilingual rehabilitation counseling staff.

The assessment of a non-English speaking individual's residual functional capacities can—and in most assessment situations does—become very



Ms. Lisa Navarro advises her client on what vocational rehabilitation rights and services are available to him.


unclear. A clear understanding by both the rehabilitation counselor and the client can only be reached through detailed discussions about that client's abilities to perform various activities. If the interviewing counselor, work evaluator, and/or test administrator are not fluent in the client's primary language, it then becomes very difficult to properly assess a client's strengths and weaknesses from a physical, intellectual and emotional perspective.

sumers is one of the examples that the ADA regulations cite to illustrate how services for persons with disabilities must be as effective as those for nondisabled persons.

Finally, there are several cultural issues that can have a dramatic effect on the ultimate outcome of the rehabilitation program. Issues such as the family support system and social perceptions regarding personal capabilities of individuals with disabilities are examples of the types of potential problem areas to which rehabilitation counselors must be sensitive.

In short, the primary issues that non-English speaking individuals with disabilities face when attempting to participate in vocational rehabilitation are not the usual decision points—such as choosing a vocational objective, selecting appropriate training or education facilities, or obtaining adaptive equipment—but rather involve having access to qualified, bilingual rehabilitation counseling staff sensitive to the cultural needs of specific clients and knowledgeable about available community resources. Non-English speaking individuals must be greeted by rehabilitation counselors with something other than, "Come back when you can speak English."

In conclusion, there is a clear need for VR agencies to develop and implement

meaningful outreach programs for non-English speaking individuals with disabilities. While the development and implementation of outreach programs is expensive in terms of both time and funds, these programs would be rendered useless without a careful structured framework in place to address this challenge meaningfully. Careful and sensitive consideration must be given to methodology. Sporadic, unstructured, diffused, and varied approaches towards implementing an outreach and services delivery system will only perpetuate the status quo. The continuation of inadequate and inappropriate service delivery systems, or even worse, lack of access to those systems, would only lead to unsuccessful outcomes for the underserved populations. 

The Americans with Disabilities Act (ADA) requires state agencies to make their services "equally effective" for their consumers with disabilities.

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Although the use of an interpreter is a reasonable approach, it is at best a highly artificial process. The use of an interpreter may create as many barriers as it resolves; introducing a third party into what should be a very personal and spontaneous process may in many cases have the opposite effect. At the VR level, it is hoped that the Rehabilitation Act's 1992 requirement that the Commissioner develop a plan to prepare minorities for careers in vocational rehabilitation will result in more bilingual and cultural-sensitive counselors. Also, the Americans with Disabilities Act (ADA) requires state agencies to make their services "equally effective" for their consumers with disabilities. Having caseworkers who can communicate directly with their clients or con-

European Congress on Research in Rehabilitation Scheduled for 1998

The 6th European Congress on Research in Rehabilitation, "Improving Practice by Research," is scheduled for May 31 to June 4, 1998, at Humboldt University in Berlin. Some 1,500 participants from all over the world are expected. The European Congress on Research in Rehabilitation of the European Federation for Research in Rehabilitation is held every 3 years.

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Latino Access to Rehabilitation Services: Evidence from Michigan

In this article, we examine factors associated with access to rehabilitation services by Latinos with disabilities. Data for this analysis were obtained from a 1990–91 pilot survey of 124 working-age Latino adults with disabilities residing in three metropolitan areas in Michigan. At the time of the interview, only 36 percent of the respondents reported having received rehabilitation services and only 34 percent reported receiving services from other agencies, primarily income support from Social Security or General Assistance.

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With the diversity of cultures represented in the United States, healthcare, rehabilitation, and educational specialists are confronted with the task of providing services to families who hold different belief systems regarding perception and causes of disability and, therefore, have different preferences for treatment. As Anderson and Feniche (1989; p. 7) underscore, "There are cultural and situational influences which, if ignored, may from the onset, doom to failure even the best intentioned programs for culturally diverse persons with disabilities and their families." Therefore, it is imperative that health delivery systems be structured in congruence with a variety of beliefs regarding the etiology and treatment of disabling conditions.

The significance of this congruence for Latinos becomes more apparent when national demographic changes are considered. According to the U.S. Census (1991), 7 percent of Americans with work disabilities were Latino. The disabled adult Latino population has been estimated to number 2.5 million—approximately 17 percent of the Latino working-age population (Suazo, 1986). The proportion of Latinos with disabilities is only slightly higher than for non-Latino whites. However, the number of Latinos with disabilities is expected to rise dramatically in the coming years as a result of sustained high levels of population growth within the Latino population and greater exposure to health and occupation risks.

Yet, relatively few Latinos participate in rehabilitation services. Only one-tenth of 1 percent of all working age Latinos with disabilities were rehabilitated by public programs in 1981 (Suazo, 1986). Wakabayashi, Ayers, Rivera, Saylor, and Steward (1977) assert that a general unresponsiveness by rehabilitation and other social service delivery systems deters the successful rehabilitation of minority persons with disabilities. As a result, Latinos and other ethnic minorities are underrepresented in the service delivery system and do not fare as well as non-Latinos and other nonminorities in relation to rehabilitation outcomes, access to services, and the quality and quantity of services (Ross & Biggi, 1986; Santiago, 1989; Wright, 1988).

The limited utilization of rehabilitation services by Latinos and other ethnic minorities cannot be solely attributed to the lack of service providers or community outreach efforts. Cultural practices, medical beliefs, and customs of the ethnic group may play a significant role in the conceptualization of normalcy, beliefs regarding causation, tolerance and acceptance of disability, and group attitudes toward the use of the government or other community resources (Cuellar & Arnold, 1983; Wilson, 1986). Furthermore, the lack of recruitment programs targeted at Latinos, the lack of adequate public transportation, and institutional devaluation of Latino culture tend to diminish participation in existing programs (Ubarry & Santiago, 1988).

Unfortunately, the paucity of information regarding services to Latinos and other minorities impedes our ability to identify fully the causes and consequences of the overall lack of participation in various rehabilitation

programs. Yet, we know that Latinos with disabilities experience extreme levels of deprivation. Bowe (1985) reports that three out of four disabled Latinos have less than a high school education. Approximately 75 percent have annual earnings which are less than \$8,000; and nearly 60 percent earn less than \$4,000. Moreover, relatively few Latinos with disabilities (17 percent of Latina women and 42 percent of Latino men) participate in the labor force (*Rehab Brief*, 1984). For those disabled Latinos who do enter the labor force, the chances of being unemployed are high: 22 percent of Latina women and 24 percent of Latino men were unemployed (Bowe, 1985).

Existing studies suggest that the problems facing minorities with disabilities are exacerbated by the social inequities of multiple minority status (e.g., Arnold, 1983). For Latinos with disabilities, this means having to cope with other positions of disadvantage based upon ethnic, racial, and linguistic differences in addition to coping with the inequities they encounter as a result of their disabilities. Being disadvantaged may lead to differences in the degree to which physical impairments and disabilities become handicaps for the individual. Moreover, differential access to available services deprives Latinos of healthcare, education, and training. Continued barriers to these services further exacerbate the precarious status of Latinos with disabilities.

As Baldwin and Smith (1984) report, most research on minority people with disabilities has focused on mental illness or substance abuse. This has been particularly true for Latinos, with relatively few studies examining the nature or extent of physical disabilities among Latinos (Luetka, 1976; Kirchner & Peterson, 1980, 1981; Arnold & Orozco, 1987; Santiago, 1988). Perhaps one of the most serious issues facing service providers is the scarcity of information about Latinos with disabilities. Extremely limited information exists about the types and incidence rates of disabilities affecting this population. Moreover, relatively little is known about the impact of the existing service delivery sys-

Perhaps one of the most serious issues facing service providers is the scarcity of information about Latinos with disabilities.

tem on the rehabilitation of Latinos, especially since so few are being served. These limitations appear to have substantially hampered the development and implementation of programs designed for Latinos with disabilities.

For the most part, research on Latinos has focused on describing cultural differences that affect their utilization of rehabilitation services (Arnold, 1983; Rivera & Cespedes, 1983; Kuncie & Vales, 1984; Gomez, 1987; Cooney, 1988; Cuellar & Arnold, 1988). These studies have provided useful cues for service providers regarding Latino perceptions of disability, values, communication norms, and the need for pluralistic counseling strategies (see Medina et al., 1988). From this work, the cultural values and norms of the client emerge as crucial elements in determining rehabilitation outcomes. For Latinos, this means that service providers need to understand the role of the family and include the family in treatment programs; practitioners must attempt to personalize the service delivery system; treatment should be goal-oriented; and counselors should be aware of protocols regarding verbal and nonverbal communication with clients. The development and acceptance of programs that are culturally sensitive to Latinos appears to foster the rehabilitation process (Ubarry & Santiago, 1988).

However, with one exception (Baldwin & Smith, 1984), these studies have generally failed to assess empirically the factors which shape demands for, and access to, rehabilitative opportunities. Specifically, Baldwin and Smith argue that access to rehabilitation is conditioned by the limitations and capacities of the individual; the individ-

ual's motivation towards work; the vocational skills of the individual; the physical, mental, and skill requirements of the job; and the environmental factors that make employment accessible or inaccessible. As they emphasize, rehabilitation in the United States can be a very selective process whereby only individuals identified as being most likely to succeed are referred to, and participate in, services. Different perceptions regarding the potential for success may result in unequal access to services encountered by racial or ethnic minorities, the poor, those with limited education or skills, and older individuals with disabilities. While these inequities have been well documented for minority recipients of mental health services, little comparable research has been undertaken to examine the inequities of service to individuals with other disabilities (Baldwin & Smith, 1984, p. 301).

In this article, factors that are associated with the access to and utilization of rehabilitation services by Latinos with disabilities are examined. The data used in this study were obtained from a 1990-91 pilot survey of 124 disabled working-age Latino adults residing in the three largest Latino communities in Michigan. The objectives of this research are to (1) identify patterns of service utilization by Latinos using the metropolitan areas of Detroit, Grand Rapids, and Lansing as test sites; and (2) identify factors associated with service utilization by Latinos with disabilities.

Method

Respondents were selected from a listing of Latino households from the metropolitan areas of Detroit, Grand Rapids, and Lansing, Michigan. A master listing of these households was gen-

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erated by the authors from the telephone and city directories of these communities and was augmented with information obtained from service providers based in these communities. From this listing, a sample of approximately 2,500 telephone exchanges was drawn at random. Each interviewer obtained a listing of approximately 200 exchanges. Each household was screened to verify Latino heritage as well as to determine if at least one member of the household was identified as having a handicap, disability, or health condition that limited daily activities. Utilizing this process, a total of 225 households were identified. From this total, 186, or 83 percent, of eligible households responded to the survey. In this study, we restrict our sample to the 124 respondents who were between the ages of 16 and 65 at the time of the interview.

Characteristics of Respondents

Approximately 66 percent of all respondents were of Mexican descent, another 17 percent were Puerto Rican, and the remainder were Cuban and Central or South American. Slightly less than half of the respondents lived in the Detroit metropolitan area. Nearly one-quarter of the households had two or more persons with disabilities. The median age of onset of the disability was 29 years, and the median age at time of interview was 44.5 years. Half of the respondents were married. Approximately 53 percent of the respondents had not completed high school. Three out of every ten households had incomes below \$15,000 in 1989.

Instrument

For the purpose of this study, we designed a questionnaire that would be sensitive to issues related to the disability as well as to the cultural identity of the individual respondent. Information about the nature and extent of disabilities within the household was obtained using a detailed disability checklist developed and utilized by Michigan Rehabilitation Services

(MRS), the public rehabilitation agency in the State of Michigan. Severity of disability was assessed using the MRS screener which identifies the ability to perform seven activities vital to independent living. In addition, open-ended questions were used to probe for respondent self-identification of their disability status as well as cultural and religious beliefs which shape individual attitudes toward their disabilities.

Additional questions focused on the sources of support available to respondents and their use of existing services. Particular attention was given to examining access to rehabilitation services. Service utilization was measured through respondent self-reports of program participation at the time of the interview. Respondents were then asked to identify and describe the types of services received. Included in this section was an item regarding use of public rehabilitation services. A final set of questions focused on respondent assessments of service needs.¹

The survey instrument was administered by a trained team of 12 (9 female and 3 male), bilingual/bicultural interviewers who were recruited from the three communities. A total of 4 months was devoted to the data collection.

Whenever possible, the interviewers administered the survey instrument to the household member who was identified as being handicapped or disabled. In the cases where this was not possible, an adult member of the household was asked to provide information about the family member with disabilities. If more than one member of the household was disabled, information was solicited first for any adults. General information about the types of disabilities was collected for all members of the household, but more detailed information was collected for only one of the household members who was randomly selected by the interviewer. Although both in person and telephone interviewing techniques were tested in the study, 96 percent of the interviews were conducted over the telephone. Approximately 43 percent of the interviews were conducted in Spanish. The average length of the interview was 30 minutes.

Chronic illnesses, such as diabetes and heart disease, were identified as the primary disability among Latino adults.

Types of Disabling Conditions

The MRS checklist identifies 29 categories of physical conditions ranging from vision problems to paralysis to heart disease and AIDS. Respondents could identify more than one condition but were then asked to self-identify their primary disability. These conditions were then collapsed into six categories: chronic illness, mobility impairment, sensory impairment, neurological disease, cancer, and mental retardation and learning disabilities. In this analysis, psychological problems were excluded from our checklist because we wanted to examine the extent of physical disabilities.²

Chronic illnesses, such as diabetes and heart disease, were identified as the primary disability among Latino adults (43 percent). Another 26 percent were mobility impaired (e.g., loss of limb, paralysis). Ten percent of the respondents had sensory impairments (e.g., blindness; deafness). Neurological diseases, such as stroke and epilepsy, affected 10 percent of the respondents. Approximately 6 percent of the respondents had cancer and 6 percent were mentally retarded or had learning disabilities. Nearly half the respondents cited disease as the cause of their disabling condition, 22 percent cited birth defects, and 30 percent cited injuries. Of those who were injured, 50 percent received their injuries on the job.

Latino Definitions of Disability

In order to further probe into respondent perceptions of disability, a number of open-ended questions were included in the interview process. Specifically, respondents were asked to identify and define their preferred term

of identification (disability or handicap) and provide any reasons, if applicable, for not seeking assistance in relation to their personal, social, financial, vocational, and independent living needs. Responses to these questions were recorded verbatim by the interviewers, and then reviewed, sorted, and categorized to provide a qualitative analysis of responses provided by all 124 respondents.

When asked to identify the term they preferred for self-identification, 41 percent (45/110) selected the term “disability,” and 46 percent (50/110) selected the term “handicap.” Responses to each of these preferred terms did not vary by Latino heritage (e.g., Mexican, Puerto Rican, Cuban). Furthermore, when asked to provide definitions of disability and handicap, respondents had similar patterns of responses. As shown in Table 1, one category, labeled “severity of condition,” appeared to capture the majority response for both terms (55 and 64 percent, respectively). Of interest, respondents who provided definitions for these terms using severity of condition criteria appeared to be assigning a distinction in the severity between the two. For example, some felt that the term disability connoted a condition

that was more severe and permanent than a handicap, while others felt just the reverse, that is, that a handicap meant something that you live with the rest of your life and disability meant you are more limited.

Relatively few Latino adults with disabilities were receiving rehabilitation services

The only categories where there were clearly apparent differences in definitions were the mobility and cognition areas. Here, respondents felt that mobility impairments constituted a handicapping condition, where cognitive limitations were identified as a disability rather than a handicap. It appears quite clear upon review of all of these responses that there is great variety in how people personally define these terms and what they perceive as the impact of impairment in terms of function and capacities. This again seems to underscore the need for edu-

cation and outreach to these communities in order to provide assistance in dealing with the impact of disability for the individual and the family.

Disability Status: Self-Reports v. Program Measures

Although all of our respondents reported some type of health condition that limited their daily activity, approximately 54 percent indicated that their health condition prevented them from going to work, school, or doing housework. Further, 6 out of 10 respondents stated that their condition limited social and recreational activities. Yet, only 65 percent considered themselves to be disabled (see Table 2). Of interest, when asked if other Latinos would consider the respondents to have disabilities, a slightly smaller percentage (61 percent) indicated that other Latinos would identify them in that way. Identification from outside the community was less certain: About 57 percent of the respondents thought that non-Latinos would consider them to be disabled.

According to the MRS criteria used for determining the severity of the disability, approximately 56 percent of the respondents would have been classified as severely disabled. Yet, only 37 percent of the respondents indicated that they considered themselves to be severely disabled. This suggests that there is a significant difference in how Latinos view the severity of their conditions relative to official definitions. Thus, it may very well be that respondents are not seeking and using services partially because they do not consider themselves to be severely disabled or eligible for services.

Patterns of Service Utilization

Relatively few Latino adults with disabilities were receiving rehabilitation services from the Michigan Rehabilitation Services, the public rehabilitation program and the primary agency providing these types of services in the state. Only 18 percent of the respondents reported that they were MRS

Table 1
Respondent Definitions of Disability and Handicap

Criteria	Definitions			
	Disability		Handicap	
	N	%	N	%
Severity of Condition	46	55.2	49	63.6
Mobility or Limb Impairment	1	1.2	11	14.3
Duration or Permanency	10	11.5	7	8.0
Ability to Work	9	11.5	6	7.8
Communication Impairment	9	10.3	1	1.3
Limitations of Cognitive Skills	9	10.3	1	1.3
Other	1	1.2	3	3.9
Total	87	100.0	77	100.0

NOTE: Due to rounding errors, percent may not total 100.

Table 2
Self-Reports v. MRS Indicators of Disability Status

Self-Reports of Disability Status	N	% of Total
Consider yourself disabled	81	65.3
Other Latinos consider you disabled	75	60.5
Non-Latinos consider you disabled	71	57.3
Self-Perceptions of Severity of Disability Status		
Consider self to be slightly disabled	26	22.0
Consider self to be mildly disabled	42	33.9
Consider self to be severely disabled	46	37.1
MRS Disability Criteria		
Cannot work 6 or more hours	52	41.9
Cannot climb 1 flight of stairs	49	39.5
Cannot walk 100 yards without pausing	38	30.7
Cannot button buttons	15	12.1
Cannot wind watch	13	10.5
Cannot write with pen or pencil	15	12.1
Cannot use mass transit	33	22.6
Severely disabled according to MRS criteria	68	55.7

clients at the time of the interview—a proportion that seems to mirror national patterns of limited service utilization by Latinos. Another 18 percent indicated that they had been former clients of MRS but were not currently receiving service. Unfortunately, the survey instrument did not include followup questions regarding the reasons for closure. When asked if they received services from other agencies, 34 percent of the respondents stated that they were obtaining other types of services. These included services from local community-based agencies offering services targeted to the Latino community; governmental agencies (e.g., Department of Social Services); private agencies (e.g., Catholic Social Services); and local churches, food banks/shelters, or places of employment.

Perceived Barriers to Services

Respondents were asked to identify their reasons for not seeking assistance. Table 3 provides a summary of the rea-

sons given by respondents. Clearly a significant barrier reflects the belief that these services are neither needed nor desired: 27 percent of the respondents indicated that services were not necessary. Further, there was a degree of skepticism regarding how useful these services would be. This feeling was

captured by one respondent who states “*No necesito ayuda. Remedios solo son temporeros* (I don’t need help. Remedies are only temporary).”

The disapproval of family members or friends was identified by 22 percent of the respondents as a significant deterrent to seeking professional assistance. As one respondent succinctly stated, “I’m scared to tell anyone what is wrong with me.” Another reported, “I’m interested in getting help as long as I could be sure my family wouldn’t find out.” The help-seeking behaviors of Latinos with disabilities in part reflects individual perceptions of what constitutes culturally acceptable channels for resolving problems within the family. “(The) family tries to help first. Extended family is next. If we can’t do it, which is rare, then we forget it. We don’t want outsiders.” Indeed, two-thirds of the respondents reported that relatives or friends provided the most help for meeting their needs. This is partially attributable to the limited financial resources and services available within the Latino community. “(The) Hispanic community doesn’t have money. Not enough resources in the Hispanic community. There is only one Hispanic treatment center and too many people go there.”

Yet, the reliance on informal support networks from within the family unit or larger Latino community transcends financial considerations. As one re-

Table 3
Reasons for Not Seeking Rehabilitation Services

Reason	N	% of Total
Does not want or feel need for service	24	26.4
Family disapproval	20	22.0
Relative/friends disapproval	16	17.6
Cost of services	8	8.8
Limited English proficiency	5	5.5
Lack of transportation	5	5.5
Does not know where to go	3	3.3
Other	10	11.0

N = 91.

spondent noted, "I would never do that—ask white people for help. I'd feel embarrassed." The use of outsiders was viewed by some to be "... an admission that something is wrong." Another respondent highlighted perceptions of how the Latino client is received within the larger community: "... when I was a kid, I was not welcomed in the (white) community."

Past research (Cuellar & Arnold, 1983; Wilson, 1986) has documented the importance of group attitudes regarding the use of government or other community resources on help-seeking behaviors. If Latinos are socialized into believing that there is something wrong with them or their families if they cannot meet their family needs and that the majority community will not welcome them or would treat them badly, it is no wonder that they are reluctant to look beyond the confines of existing informal support networks. Therefore, it is clear that client perceptions of how they will be treated both inside and outside the community are still important considerations that must be addressed by service delivery agents attempting to provide service to Latinos with disabilities.

Limited accessibility in terms of cost, transportation, knowledge about services, and availability of bilingual services, were reported as barriers by nearly one-quarter of the respondents. In the survey, 9 percent of the respondents mentioned cost of services as a deterrent. As one respondent mentioned, "If the doctor doesn't take insurance, you may not wish to try another." The lack of transportation to and from services was also a factor reported by 6 percent of the respondents. As one respondent described, "If she had to go by herself, she couldn't get there because she can't drive." Access can also be hampered by a lack of knowledge regarding the availability of existing services. Several respondents simply stated, "I don't know where to look for help."

The limited availability of bilingual/bicultural services hindered about 6 percent of Spanish-dominant respondents from seeking service, highlighting

the continued importance of Spanish speaking staff to provide a bridge between clients and service providers. Previous studies have documented the ongoing need for bilingual/bicultural direct service staff as well as sensitivity training for English speaking staff in order to better understand client needs and concerns (Medina, et al., 1988; Ubarry & Santiago, 1988).

Factors Mitigating Participation in Rehabilitation Services

In a multivariate analysis summarized here, we examine how participation in rehabilitation services was affected by factors such as geographic accessibility, the severity of disability, the existence of alternative belief and support networks, and respondent characteristics.³ This analysis reveals that differences in the demographic characteristics of respondents and cultural factors were significant predictors of the receipt of rehabilitative services. The odds of receiving services were about 86 percent lower for Puerto Ricans relative to Mexican respondents. Further, respondents who had higher levels of educational attainment also had higher odds of service receipt. Respondents who were high school graduates had 4 times higher odds of receiving MRS services than respondents with less than high school degrees. There was also a significant age effect: younger adults were more likely than older adults to receive services. For each additional year in age, the odds of receiving rehabilitative services declined by 7 percent.

Cultural belief systems significantly impacted the receipt of rehabilitation services although not in the expected manner. Respondents who indicated having strong cultural beliefs that would limit service utilization had 10 times greater odds of receiving services than those who did not indicate cultural limits to service utilization. Thus, although a fraction of our respondents indicate that they reside in families with strong cultural values discouraging the use of outside help, these beliefs were not enough to prevent the use of

services. This would suggest that although these beliefs may be strong, respondents may not be in a position to adhere to them. In other words, Latinos may state a preference to seek help from within their informal support networks or alternatively from community-based organizations, but the severity of the disabling condition or the lack of resources within the Latino community will compromise these beliefs.

Discussion

The purpose of this study was to investigate how the support systems available to Latinos with disabling conditions affect their utilization of rehabilitation or other services. Several observations can be made from the findings of this study which have direct implications for rehabilitation service providers and other related health professionals. First, relatively few Latino adults with disabilities in the sample were actively receiving rehabilitation services at the time of the study. In fact, only 18 percent were served by the public rehabilitation program in 1991. An additional 18 percent indicated they had formerly received vocational rehabilitation services from the state agency, and approximately 34 percent of the sample were currently receiving various support services from other community agencies. When considering the general characteristics of this sample, these utilization rates take on great importance. Clearly, a gap between service utilization and the need for services exists for Latino adults with disabilities in this sample.


While this pattern of underutilization may be perceived as somewhat surprising, it is similar to findings reported in previous research. Anderson, Zelman, Giacnello, Aday, and Chiu (1981), for example, reported that even when adjusted for medical need, Mexican Americans were less likely to visit doctors and to have preventive health examinations than non-Mexican Americans. Similar patterns of underutilization of health facilities for Puerto Ricans and low-income patients in New York have been reported by Alers (1978).

In order to probe those factors contributing to this gap in service utilization, the patterns and determinants of service utilization were also examined. Age of respondent, educational attainment, Latino heritage, and cultural limitations were found to be the most significant predictors of service utilization by Latinos with disabilities. Increasing age and being Puerto Rican were associated with lower odds of receiving vocational rehabilitation services. Conversely, those individuals with disabilities who have higher skill levels were more likely to receive rehabilitation services. Ironically, individuals that indicated cultural belief systems limiting the use of outside services had higher odds of receiving services than those who did not have these restrictions.

It is important to note, however, that the patterns of underutilization noted within this investigation may in fact be related to self-perceptions and levels of acceptance of the severity of the particular handicapping condition. Specifically, only 37 percent of the 124 respondents in this investigation viewed themselves as having a severe disabling condition. Yet, when the information from the MRS screener was reviewed, 56 percent of these persons were considered to have a severe disabling condition. As previously mentioned, one possible explanation for the differing interpretations may lie in the fact that the term "disability" covers a broad range of physical and mental impairments.

Unfortunately, the pattern of underutilization noted herein indicates that, despite efforts, characteristics of Latino social life and subcultural values continue to deter professional services for Latinos. Information provided in previous research suggests that several factors, which are possibly related to the underutilization of services, are subsumed under the categories of cultural support systems (i.e., as characteristics of Latino social life and subcultural values that make professional services unattractive to Latinos), as well as institutional factors, such as the characteristics of agencies and of the social welfare system that discourage Latinos from using these services. As evidenced within the

current investigation, however, it is clear the issue is not one or the other but, rather, a combination of both factors.

In terms of implications for service providers, these data would support the need for creative outreach efforts within the Latino community in order to enhance service utilization by adults with disabilities, particularly those who are least likely to be aware of and to independently pursue available services. The notion that service utilization is significantly affected by the cultural beliefs and values of the Latino community was supported in this study although the relationship was not what was expected. As the literature has consistently indicated over the past decade, cultural factors may indeed have an important impact on the client's rehabilitation process if not on utilization directly once services have commenced. Responding to these issues, the field of rehabilitation has generally agreed on the importance of rehabilitation counselors and the service delivery system to be aware and sensitive to the client's cultural and family background in the selection of service and intervention efforts that enhance rehabilitation outcomes for this population. In this regard, more emphasis has been placed in recent years on attracting bilingual and culturally sensitive counselors into the system to provide needed services. However, in addition to these critical needs, the findings of this study underscore the importance of developing mechanisms to educate the Latino community about the nature, extent, benefits, and availability of rehabilitation services as well as to design outreach efforts that enhance accessibility to these services in order to increase the participation of Latino adults with disabilities in the rehabilitation process. 

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Notes

1. Copies of the survey instrument, disability checklist, and MRS screener utilized in this study are available from the authors upon request. All instruments were initially developed in English and then translated into Spanish. In order to assure that the items were conceptually and structurally equivalent, the Spanish instrument was then translated back into English. Both instruments were pretested with small, non-random samples of Latino individuals with disabilities.

2. The decision to exclude psychological problems from the checklist was predicated on the assumption that help-seeking behavior would be vastly different for the two broad types of disabling conditions. We suspected that Latinos would be less reluctant to seek help for physical conditions than they would for psychological problems because of the stigma attached to the latter. Further, we believed that it was important to devote attention to physical conditions since the limited research on Latinos has tended to focus almost exclusively on psychological problems.

3. A detailed description and results from this analysis are available upon request from the authors.

CARF Establishes Web Page

As a first step towards taking advantage of the vast resources available on the Internet, CARF (The Rehabilitation Accreditation Commission) has established a World Wide Web site, accessible at <http://www.carf.org/>. This site will provide CARF with the capacity to communicate with the constituencies in the rehabilitation field and with the general public.

The page is designed to provide easy access to a substantial body of up-to-date information about CARF, CARF accreditation, and current issues in the field of rehabilitation and is structured around CARF's main areas of service: behavioral health, employment and community support services, medical rehabilitation, education and training, and research and quality improvement.

In each of these areas, the CARF site will provide news from the field, major trends or undertakings by CARF, calendar of upcoming events, upcoming seminars/conferences, and a catalog of publications available for purchase.

In addition, a general purpose section will provide information regarding the structure of CARF, CARF's mission, CARF's Board of Trustees, basic steps in the accreditation process, CARF's accreditation outcomes, who helps with what at CARF, links to other rehabilitation related resource sites, and more.

You may contact CARF at webmaster@carf.org with any questions and/or comments.

Ron Bourgea: An Appreciation

Ron Bourgea, founding editor of *American Rehabilitation* and editor of its predecessor, the *Rehabilitation Record*, died February 21 in his home in Gaithersburg, MD. He had cancer.

Ron served as editor of the official journal of the Rehabilitation Services Administration (RSA) through a number of organizational changes. It was his dedication and his incredible discipline which kept the journal functioning through some of its most trying years.

Born on Sept. 9, 1927, in Nashua, New Hampshire, Ron married his childhood sweetheart, Marguerite "Peggy" Shanahan, in 1946. He joined the Navy in 1945 at the age of 18 and became a corpsman. He retired from the service as a Chief Petty Officer in March 1965. For several years early in his Navy career he was managing editor of the *NNMC News* (now known as *The Journal*) of the National Naval Medical Center in Bethesda, MD, where he also served as a librarian. He again was managing editor of the *NNMC News* from 1961 until his retirement from the Navy.

He personally saved the lives of at least three people. In Cuba, when Ron was about 20 years old, he resuscitated a sailor who had nearly drowned. Three years later, he saved the life of a 1-year-old girl who had stopped breathing. Not knowing exactly what to do, he did the right thing instinctively. He turned the child over on his lap and gave her artificial respiration. She coughed, cried, and began to breathe. Sometime in the early 1970's, during Ron's commute home from Washington, DC, a man on his train had a heart attack and all of his life functions ceased. Ron brought him back with CPR.

In 1967, when he began his federal service as assistant editor of the *Reha-*



Photo by Steven J. Bienstock

1927-1996

bilitation Record, the agency which then administered the state-federal vocational rehabilitation (VR) program was called the Vocational Rehabilitation Administration (VRA). Dorothy Rigdon was then editor of the *Rehabilitation Record*. Mary Switzer was Commissioner of VRA. Ron always referred to this time as the agency's golden years. In 1971, when VRA became RSA under the Social and Rehabilitation Services Administration (SRS), Ms. Switzer became the first SRS Administrator and, after Ms. Rigdon's retirement, Ron was appointed editor. Shortly thereafter, RSA's Office of Public Affairs, including the *Rehabilitation Record*, was merged into the SRS Office of Public Affairs. These were difficult

times for RSA's journal. The *Rehabilitation Record* was absorbed by a new, short-lived publication, the *Social and Rehabilitation Record*, and Ron was appointed its editor. The journal at this point ceased its rehabilitation focus and Ron was obliged to use articles on welfare, aging, juvenile delinquency, migrant workers, and others, along with one or two on rehabilitation in each issue. In spite of this, Ron's complete devotion to rehabilitation continued and he fought to include as many rehabilitation articles as possible in the new journal. More reorganizations followed. Shortly after RSA's Office of Public Affairs was reestablished in RSA, Ron immediately sought to resurrect RSA's journal with its focus

on disability and rehabilitation. In 1975, Ron gave birth to *American Rehabilitation*; he served as its editor until his retirement on December 31, 1985.

For a brief time—a very brief time—it was difficult for me to imagine Ron as anything but the editor of RSA's professional journal. But through the years, as I grew to know and love him, I learned that he excelled in many arenas. He spoke French fluently. As a U.S. Navy corpsman, he delivered babies and performed appendectomies and countless other emergency medical procedures when a physician was not available, especially during those years when he and his family were stationed on Kwajalein Atoll in the Marshall Islands. Before it became the hospital ship *HOPE*, Ron served aboard the hospital ship *USS Consolation* and vaccinated thousands of children against polio and other diseases and was instrumental in establishing vaccination clinics throughout the world that are still in operation as EPI (Expanded Program on Immunization) clinics under the World Health Organization. He wrote beautiful poetry. After Dr. Christiaan Barnard performed the first successful human heart transplant in 1967, Ron wrote a play, "Have a Heart," which was published and performed for many years in community theaters throughout the United States. He was the chief drama critic for the *Gaithersburg Gazette* for a number of years, wrote novels, and painted. He was proficient in American Sign Language.

His compassion, both for his fellow man and for all living creatures, was endless. He once kept a female praying mantis alive throughout the winter by feeding her pieces of steak and insects. When his children were small, he bought a dime store turtle for one of his daughters, but cautioned the clerk not to paint anyone's initials on the turtle's back, as was the custom when selling these turtles years ago. He explained that the paint was toxic to the turtle. Just as he did with the praying mantis and with *American Rehabilitation*, Ron "bonded" with the turtle, whom the family named "Frisky," and soon it was his. After reading a newspaper article

about disease carrying turtles and salamanders, Peggy insisted that he release Frisky into the wild because she feared that the turtle might be carrying a disease that could infect the children. Ron, like the good husband he was, resolutely took Frisky with him and drove out to the country. Later, he returned with Frisky and explained that when he threw Frisky into the water the turtle would swim back to him. He told Peggy that he threw Frisky into the water again, only further; but again Frisky returned. Ron then said that after a couple of more useless attempts he finally decided to give up, and that was why he came back with Frisky. He cared for Frisky and watched him grow for 15 winters, until the turtle was about 15 inches across. He did finally manage to release Frisky. This time he did not throw him into the water, but gently placed him at the water's edge.

Ron was an avid gardener and a consummate nature watcher; he could watch bugs for hours. He could recognize most birds, and every Sunday he and Peggy would drive out to the mountains in western Maryland to silently observe the deer, birds, and other wildlife and, later, to check on how Frisky was doing. It has occurred to me more than a few times that, perhaps, Ron occasionally comes back for a brief visit and to check on how *American Rehabilitation* is doing.

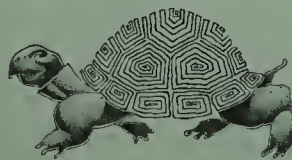
Ron is survived by three daughters—Shannon, Renée, and Lisa—one son, David, seven grandchildren—aged 10 to 27—a sister, Mrs. Maxine Horne, and too many friends to count. Peggy died of cancer 6 years earlier. We all miss them beyond words.

Frank Romano, editor,
American Rehabilitation

AWAKENING

*SLEEP in my eyes! The slow awakening
Into another time and world and place;
What matters all the songs I sang aloud
About the deeds of knight, or saint, or king?
I sang them yesterday, but now I face
New heaven. New the heaven's cloud.
I lately woke from dreams of wealth and fame.
I lately woke from dreams of life and death.
I lately woke from dreams of love and hate.
Today comes slowly, as though it were a shame
To think of yesterday, or dream its breath
Could do no more than mirror time and fate.
I wake. Slow steps, accounted yesterday,
Are yesterday's. A world awaits today.*

—Ronald Bourgea



American Indian Vocational Rehabilitation Services: A Unique Project

Bruno J. D'Alonzo, Ph.D.
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Wayne Oyenque, L.M.S.W.

Although there are multiple, effective models for providing rehabilitation services to persons with disabilities, the extension of these models to American Indians is complicated by cultural diversity and geographically limited accessibility. These two factors, as well as corollary problems that hinder the provision of services to American Indians, are reviewed. A unique, collaborative project is described in which paraprofessionals who spoke the native languages assisted with vocational rehabilitation services in American Indian clients' communities.

An extensive investigation of the prevalence of disabilities among American Indians resulted in the following data (O'Connell, 1987):

- American Indians had a disproportionately high incidence of disability.
- American Indians had a disproportionately high rate of unemployment.
- The percentage of American Indians employed in low scale jobs was disproportionately high.
- Among American Indians who were employed, a disproportionately high incidence of disability occurred on the job.

These results were corroborated by data reviewed by Kuehn and Imm-Thomas (1993). Their investigation was a response to an observed correlation between the rate of infants born with low birth weights in a population and the percentage of individuals who subsequently exhibited developmental disabilities within that population. Though the percentage of American Indian infants with low birth weights was comparable to that in the general population, there were significantly higher mortality rates for both neonates and adults among American Indians. The combined effects of these statistics was interpreted as an indication of a greater proportion of developmental disabilities among American Indians.

Other examples of disabling conditions that have been reported as occurring with unusual frequency among American Indians included alcoholism

(Kivlahan, Walker, Donovan, & Mischke, 1985; May, 1986; 1988), mental health problems (May, 1987; 1988), communication disorders (Thielke & Shriberg, 1990), drug and substance abuse (May, 1986), depression (May, 1987), fetal alcohol syndrome (McShane, 1988), and the early display of symptoms associated with aging (Martin, White, Saravanabhavan, & Carlise, 1993). Although the incidence of such disabling conditions has been reported as higher among American Indians as a group than among the general population, there can be significant variability in rates of occurrence between tribes (Justice, 1987) and among members of the same tribe. Variability in rates of incidence for disabilities among American Indians has been linked to age as well as social and economic factors (Logue, 1990).

Some critics (Morgan, Guy, Lee, & Cellini, 1986; Morgan & O'Connell, 1985; Toubbeh, 1987; 1989), observing the prevalence of severe disability among American Indians, have argued that American Indians should receive priority as clients for effective rehabilitation programs. However, traditionally organized and delivered rehabilitation programs have been largely unsuccessful with American Indians. Because of the incongruity between the assumptions on which these programs are based and the assumptions on which the beliefs of American Indians are founded, critics of traditionally organized programs have even questioned whether such programs constitute a barrier rather than a pathway to rehabilitation.

Cultural Diversity

Recounting case studies of American Indians, Joe and Malach (1992) highlighted the distinctive linguistic patterns and cultural values that can prevent the simple extrapolation of intervention models of rehabilitation. On the basis of distinctive features of American Indians, they emphasized the need for family centered assessment and intervention. They advised that service models be implemented by professionals who are sensitive to the social, psychological, philosophical, and spiritual values of American Indians. After reviewing case studies of several American Indians with disabilities, O'Connor (1993) noted that, "... to better understand the meaning of services to Indians, it is important to look not only at programs, but also at the cultural background of the people using the services..." (p. 315). Locust (1988) recommended that practitioners develop a rapport with their clients, attempting to view their clients' disabilities from a perspective within the culture of American Indians. The National Indian Council on Aging (1981) stressed the need for culturally sensitive services as well as the inclusion of American Indians themselves in both planning and implementation. Recognition of clients' legal right to participate in the planning of services that affect them can be extended beyond American Indians to all individuals with disabilities, irrespective of their ethnic origin or the severity of their disabilities (Gerry & Mirsky, 1992).

Levy (1987) stressed that beliefs between tribes can be sufficiently distinct to influence responses to medical services. As an example, distinct assumptions about the cause of epileptic seizures by Pueblo and Navajo Indians may have been responsible for the greater number of social and emotional problems exhibited by Navajo Indians with epilepsy. Other investigators have examined the possibility that shared group values of American Indians have influenced their perceptions of visual impairment (Lowrey, 1987) and emo-

tional disturbances (Scruggs & Mastropieri, 1985; Thomason 1991; Trimble & Fleming, 1989).

... counselors viewed sensitivity to their clients' cultures and communities as essential components of effective intervention.

A survey of vocational rehabilitation counselors who worked with American Indians (Martin, Frank, Minkler, & Johnson, 1988) indicated that the counselors viewed sensitivity to their clients' cultures and communities as essential components of effective intervention. Although this sensitivity was noted by counselors who worked with clients on the reservation as well as counselors who worked with clients off of the reservation, cultural sensitivity was evaluated as more important by the counselors who worked with clients on the reservation. A culturally adapted network of community support was judged to be critical for all American Indians during the phase of rehabilitation that followed counseling.

Geographical Isolation

Hodge and Edmonds (1988) described vocational rehabilitation projects for American Indians on three reservations. Recipients of services, for whom the average age was the early thirties, were unemployed, living in poverty, and receiving medical care. In addition to lack of adequate finances, inadequate transportation resulting from geographic isolation was identified as a major obstacle to counseling and rehabilitation. Joe (1988) argued that many

rehabilitation services were inaccessible to American Indians because of bureaucratic confusion among agency personnel about their responsibilities and because of the geographical remoteness of many American Indians.

There have been several rehabilitation models that have been based on cultural sensitivity and limited geographical accessibility. Family based systems of care (Cottone, Handelsman, & Walters, 1986; Emener, 1991; Joe & Malach, 1992; O'Connell, 1985) involved family and agency collaboration to ensure that services would be available in rural communities when professionals were not accessible. Other models have developed progressive empowerment, with American Indians being trained as paraprofessionals or professionals (Runion & Gregory, 1984; Stuecher, Grossman, Hakala, & Kizlowski, 1985). There were still other models that have been built on collaboration between paraprofessionals or professionals, who may or may not have been tribe members, and who had been trained about the distinctive needs of American Indians receiving rehabilitation (Martin, White, Saravanabhavan, & Carlise, 1993; Yukl, 1986). After reviewing a survey of 17 American Indian vocational rehabilitation projects, Lonetree (1990) called attention to a conclusion formed by proponents of all of these models: effective models require cooperation between state, federal, and tribal agencies.

Models for delivering services to American Indians are somewhat comparable to rehabilitation models for persons representing a broad multicultural

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background (Christensen, 1989; Dodd, Nelson, Ostwald, & Fischer, 1991; Levine, 1987; Lynch & Hanson, 1992). For example, though the culture, values, attitudes, and language of minority groups can be distinct, sensitive and flexible responses to these factors are conditions for effective rehabilitation. Consequently, vocational rehabilitation counselors who are trained with models for American Indians should be able to adapt those models for persons from other minority groups. Nonetheless, there is still a distinct and critical characteristic that distinguishes service models designed for American Indians. This distinct feature is responsiveness to clients who are usually in geographically inaccessible locations.

Kuehn and Imm-Thomas (1993) identified five critical issues that needed to be examined before service delivery models developed with non-minority populations could be extrapolated to American Indians and other minority groups. These issues comprised availability, access, cost effectiveness, accommodation, and cultural appropriateness. Two of these factors, accommodation—which refers to the interpersonal attitudes of professionals within service agencies—and cultural appropriateness, are linked directly to the backgrounds, values, and attitudes of agencies' clients. In the case of American Indians, availability and access are linked inextricably to problems of geographical remoteness. And if one considers pervasive poverty as a factor that intertwines with the backgrounds, values, and attitudes of adults with disabilities, cost effectiveness could have an influence as significant as culture (Traustadottir, Lutfiyya, & Shoultz, 1994).

A Unique Vocational Rehabilitation Services Project

The American Indian Vocational Rehabilitation Services Project followed a pilot study developed through an agreement with the All Indian Pueblo Council. It involved collaboration between the New Mexico Division of Vocational Rehabilitation and American Indian tribes

in New Mexico. Its goal was to provide individual vocational rehabilitation services to American Indians at 19 pueblos and on two Apache reservations. The American Indians at each of the 19 pueblos are members of sovereign, federally recognized tribes. The constituents of these tribes are extremely heterogeneous, exhibiting diverse cultures and speaking diverse languages. In addition to Spanish and English, residents of the various tribes communicate in seven indigenous American Indian languages (Apache, Keresan, Tewa, Tiwa, Towa, Navajo, and Zunian).

The obstacles included language, geographic isolation, transportation, inadequate rehabilitative services, and lack of available jobs.

Preproject Survey

Originally funded in 1987, the project followed an exhaustive investigation of the rehabilitation needs of American Indians of Pueblo descent or other American Indians residing within the Pueblo communities. The subjects of this investigation were 117 residents who were interested in being referred for rehabilitative services. As an example of the linguistic diversity of this group, 34 percent of the respondents requested that the interviewers use their native language during the interview; and 74 percent of the interviewed persons indicated that they actively used their native language.

Nearly three-fourths of the interviewed persons were in financial crises and the majority did not have medical insurance. Most of the respondents were not employed; and those who had been employed recently reported mean salaries of \$8,000 a year. More than half of the respondents were unemployed and not actively seeking jobs. Among persons actively searching for jobs, one-third had been searching for over a year. The disabilities they reported during the interviews included physical problems, nervous system disorders, mental disorders, emotional problems, and alcoholism. Some of the reported problems were the result of accidents and others resulted from developmental disabilities.

Based on the interviews, the project personnel identified barriers that hindered the implementation of rehabilitative services to American Indians. The obstacles included language, geographic isolation, transportation, inadequate rehabilitative services, and lack of available jobs.

Project Overview

Following the survey, a unique project was implemented. The project was intended to provide concerted services in vocational rehabilitation that would be delivered in an alternative fashion. This specific model was linked to the survey's results as well as a conviction that American Indians had been underserved in the past. Adaptations to traditional models of service delivery were designated as a means of reducing or eliminating the barriers identified by the respondents to the preproject survey.

Culture was not identified as a barrier so much as an inevitable aspect of the diversity that characterized the populations of New Mexico. For example, there are 22 federally recognized Indian tribes within the state, including 19 Pueblo Indian tribes, 2 Apache tribes, and a large segment of the Navajo Nation. Rehabilitation agency personnel made the distinction that culture was not a barrier, hoping to characterize a positive philosophy of multiculturalism on the part of the agency. Clearly,

agency personnel understood that a monolithic approach to providing services to multicultural populations would represent a genuine threat to any service system model.

To ensure that cultural diversity strengthened rather than challenged the project, rehabilitation technicians were employed. The rehabilitation technicians were paraprofessionals drawn from the Indian tribes. The technicians spoke the languages used in the pueblos and were committed to providing services in clients' own communities. This model was viewed as an avenue to culturally sensitive services that would circumvent problems associated with geographical isolation, transportation, communication, and the accessibility of services. Since an explicit goal of the project was to prepare individuals for employment opportunities in their own communities, the problems posed by inadequate jobs could be reduced as well. Additionally, members of the tribes would participate in the design and delivery of services through the feedback they had provided on the pre-project survey. They would also participate through opportunities to serve as rehabilitation technicians and through opportunities for ongoing dialogue with the rehabilitation technicians.

An additional problem identified by agency personnel was a history of reluctance within many American Indian families to refer persons with disabilities for services. The ongoing presence of paraprofessionals who themselves were residents of the pueblos was intended to raise the likelihood that referrals would be made.

The training and service of American Indian paraprofessionals was intended to have an impact on the clients with whom they would interact. However, another explicit goal of this project was that the rehabilitation technicians would in turn expand the cultural awareness of agency personnel. The project therefore became a two way conduit, with opportunities for agency personnel as well as clients to benefit.

Training of the Technicians

Nine persons served as rehabilitation technicians in this project, and each was guided by a vocational rehabilitation counselor. They met with counselors individually and in groups to discuss the clients assigned to them. Additionally, the rehabilitation technicians attended monthly meetings for inservice training. These activities were supervised by a project coordinator—an American Indian who had been designated from within the project plan area.

The responsibilities of the rehabilitation technicians were to provide culturally sensitive services in: (1) client referral, (2) vocational goal setting, (3) implementation of *Individualized Written Rehabilitation Plans* (IWRP's), and (4) job placement. Support training for the technicians focused on topics that were prioritized as needs by project staff at other American Indian vocational rehabilitation service projects as

well (Lonetree, 1990). Some of the topics included in this training were:

- vocational evaluation
- sheltered employment
- rehabilitation terminology
- medical terminology
- establishing resource contacts
- job analysis
- job placement
- foundations of vocational rehabilitation
- medical aspects of disabilities
- vocational rehabilitation legislation
- development of *Individualized Written Rehabilitation Plans*
- confidentiality

The writing of reports was another key topic for inservice training identified by the project coordinators. But this topic was scheduled for later implementation.

Characteristic of the training as well as the overall project are listed in Table 1.

Table 1
Characteristics of the Model Used in the American Indian Vocational Rehabilitation Services Project

1. The project required collaboration between a vocational rehabilitation agency and American Indian tribes.
2. American Indians were empowered to make decisions about the project.
3. Services were provided in native languages.
4. Services were provided in communities.
5. The project director was an American Indian.
6. Paraprofessionals were drawn from the American Indian communities.
7. Paraprofessionals received systematic training.
8. Paraprofessionals received sustained technical support.
9. Rehabilitation was linked to community employment.
10. The project's American Indian personnel had opportunities to influence the attitudes and values of other agency personnel.
11. The continued presence of paraprofessionals encouraged the perception that services were sustained and available despite changes in governance personnel within the Indian communities.
12. The presence of American Indian paraprofessionals in their own community encouraged referrals from families who might otherwise have been reluctant to make referrals.

Table 2
Total Number of American Indians Who Applied for Vocational Rehabilitation Services in New Mexico During a 13-Month Period¹

Type of Impairment	Number of Persons
Blindness and Visual Impairments	9
Deafness and Hearing Impairments	28
Limb Impairments	102
Loss of Extremities	7
Psychological and Mental Problems (including alcoholism and drug addiction)	212
Miscellaneous Disorders	57
Total	415

¹ Beginning of January 1993 through the end of January 1994.

Impact of the Project

As an indication of this project's impact, one can examine data from American Indians applying for vocational rehabilitation services in New Mexico. Table 2 identifies the 415 American Indians who applied for services during a 13-month period ending in January 1994 (New Mexico Division of Vocational Rehabilitation, 1994). The applicants are characterized by disabling conditions.

Table 3 indicates the rehabilitation status of the 415 American Indian applicants at the end of the 13-month period. The categories in Table 3 represent a rough chronology of the rehabilitation process. That process can end in cases being closed successfully by the agency as a result of services, training, and job placement. The table can be viewed as a snapshot of an ongoing process. Because rehabilitation is a dynamic process, the applicants were in varying stages of review and rehabilitation when these data were assembled. For example, at the end of the period, 41 referrals had been initiated that had still not resulted in formal applications, 31 cases were being reviewed, 8 cases were receiving extended evaluations, and 75 applications had been closed because applicants did

not qualify for services. An examination of one of the final entries in this table—the number of applicants who were successfully employed at the end of the period—indicates that 39 of the 415 total applicants were employed successfully. These figures are limited to progress made by clients during a 13-month period, and additional cases of successful employment certainly emerged during subsequent periods.

Table 4 contains information about those American Indians who applied for vocational rehabilitation services through the *American Indian Vocational Rehabilitation Services Project* during the 13-month period ending in January 1994. As such, the persons described in Table 4 are a subset of those in Table 3. The table indicates that all 39 clients who were employed at the end of the period had been associated with the *American Indian Vocational Rehabilitation Services Project*. Equally impressive, 32 of these 39 successful clients had

Table 3
Rehabilitation Status of American Indians Who Applied for Vocational Rehabilitation Services in New Mexico During a 13-Month Period¹

Rehabilitation Status	Number of Persons
In Process of Being Referred to VR Agency	41
Applying for VR Services	31
Receiving Extended Evaluation	8
Application or Referral Closed Prior to VR Services	75
Development of <i>IWRP</i>	56
Unsuccessfully Closed Cases After <i>IWRP</i>	15
Receiving Counseling	26
Receiving Training	54
Ready for Employment	12
Supported Employment	18
Services Interrupted	8
Unsuccessfully Closed Cases After VR Services had Been Initiated	32
Successful Employment after VR Services had been initiated	39
Total Applicants	415

¹ Beginning of January 1993 through the end of January 1994.

Table 4

Status of Persons Who Applied for Services Through the American Indian Vocational Rehabilitation Services Project During a 13-Month Period¹

Rehabilitation Status	Number of Persons
In Process of Being Referred to VR Agency	3
Applying for VR Services	15
Receiving Extended Evaluation	0
Application or Referral Closed Prior to VR Services	31
Development of IWRP	24
Unsuccessfully Closed Cases After IWRP	0
Receiving Counseling	3
Receiving Training	14
Ready for Employment	0
Supported Employment	1
Services Interrupted	1
Unsuccessfully Closed Cases After VR Services Had Been Initiated	0
Successful Employment After VR Services Had Been Initiated	² 39
Total Applicants	131

¹ The 131 applicants described in this table were a subset of the 415 applicants identified in Table 3.


² All of the 39 successfully closed cases during the 13-month period, identified in Table 3, were associated with the *American Indian Vocational Rehabilitation Services Project*; 32 of the successful cases were associated with the American Indian paraprofessional teams.

been involved with the American Indian paraprofessional teams.

The preceding data indicate clearly the project's positive impact. The 39 persons who had successful jobs worked an average of 29 hours per week. The mean hourly wage had been \$4.52 an hour; and the mean weekly wage had been \$130.16.

Summary

A review of the literature concerning rehabilitation of American Indians indicated that the extension of vocational rehabilitation services to American Indians with disabilities is complicated by cultural, geographical, social, linguistic, and financial problems. A unique project was described that was built on col-

laboration between the New Mexico Division of Vocational Rehabilitation and American Indian tribes in New Mexico. The project employed American Indians who communicated to persons in their native languages while providing services in the communities of those American Indians. The American Indians who received rehabilitation services were empowered to make decisions about the project and the project's American Indian personnel had opportunities to influence the attitudes and values of other agency personnel. Data were reviewed indicating that all American Indian rehabilitation clients in the state who were successfully employed at the end of the review period were associated with this project. 

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The Howard University Research and Training Center: A Unique Resource

Sylvia Walker, Ed.D
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Introduction

Dr. Paul Leung (1993) addresses the changing demography of the United States and the manner in which that change will affect state/federal vocational rehabilitation. During the last decade, the population of the United States has changed significantly with regard to its ethnic, racial, and cultural backgrounds. According to the 1990 Census, the U.S. population percentages are: white Americans 76.3 percent; African Americans 11.5 percent; Hispanic Americans 8.6 percent; Asian Americans 2.8 percent; and American Indians 0.7 percent. Because of this shift, vocational rehabilitation as well as other service delivery programs must respond to these demographic changes if they are to be effective. Reports on the prevalence of disability suggest that minority people with disabilities represent a substantial proportion of the total disabled population of the United States.

Data reveal that there is a decline in Americans identifying themselves as white (80.3 percent). There was also an increase in immigration in the 1980's. These changes in demography indicate that various rehabilitation delivery systems must be able to accommodate diversity within the organizational structure. Demographic changes present the challenge of shifting from a clientele



with similar values and views to a more diverse and different population of perspectives, world views, and varying rehabilitation service needs.

While it is true that individuals with disabilities who are members of racial and ethnic minority groups encounter the same challenges as other individuals with disabilities, these persons face special and unique problems because of socioeconomic, health, cultural, and other factors. In addition, prejudice, discrimination, and economic barriers continue to exclude a great number of minority persons from full participation in all aspects of society. However, relatively little research has been conducted to examine specific variables relative to ethnicity, disability and health status, income, education, geographic location, employment, and marital status.

Research conducted by Bowe (1991a), Thornhill and HoSang (1991), and Walker (1995) has documented the fact that disability is significantly higher

among African Americans and other minority groups. The poverty rate for African Americans (31.37 percent) and Hispanics (29 percent) is almost three times as high as it is among whites (11 percent) in America. Data concerning poverty rates are consistent across all age groups. The correlation between low socioeconomic status and disability is well documented; thus, low socioeconomic status families are at greater risk for disabilities throughout the life cycle (including the pre-, peri-, and post-natal periods). During the 1980's, the number of poor minority children and other dependent populations increased substantially.

The problems of non-white persons with disabilities are indeed complex: not only do they face excessive economic burdens, but they are also deprived of adequate educational opportunity. In many instances, access to healthcare facilities, community agencies, stores, schools, and transportation can only be acquired through the use of extreme measures. In addition, language, cultural, and attitudinal barriers impede access to needed resources. As a result of these circumstances, the minority person with a disability frequently finds himself/herself set aside from the mainstream of everyday life. The unique status of non-white per-

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sons with disabilities tends to compound their disability problems.

Research conducted by Bowe (1991 a + b), O'Connell (1987), and Walker (1991) reveals that a substantial number of minority persons with disabilities are clustered in specific geographic locations. For example: at least 50 percent of all African Americans live in the south, 40 percent of Hispanics reside in the west and southwestern regions of the United States, whereas, approximately 46 percent of the American Indian population live on reservations (Asbury, Walker, Maholmes, Rackley, & White, 1991). Geographic distribution and available resources have significant implications relative to the provision of healthcare, special education, rehabilitation, and related services.

Background

The Howard University Research and Training Center for Access to Rehabilitation and Economic Opportunity (HURTC) is a component of the School of Education at Howard University. Located on the university's West Campus, HURTC, established in 1988, is one of approximately 50 research and training centers supported by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.

HURTC has the philosophy that every individual, no matter how severely disadvantaged or disabled, can benefit from competent appropriately designed rehabilitation and related services. The program of the center focuses on an interdisciplinary collaborative approach to the needs of disabled persons from multicultural communities. HURTC views itself as a catalyst for bringing attention to the needs of people with disabilities from diverse racial/ethnic backgrounds.

The mission of the center is to implement research and training activities that facilitate the attainment of maximum potential by persons from diverse racial ethnic groups, including African Americans, Hispanic Americans, Americans of Asian descent, Pacific Islanders, and American Indians.

Given the compounding effects of minority group status and disability, the mission of the center encompasses four focal areas:

- assessing through research the specific needs and status of persons with disabilities and from multicultural communities;
- reducing barriers through the development of appropriate service delivery models;
- facilitating greater consumer empowerment and independence through employment and self-advocacy; and
- facilitating the training of persons from diverse cultures in the fields of rehabilitation and related services.

Minority people with disabilities continue to represent a substantial proportion of the population with disabilities.

HURTC Research Focus

Research and training activities are conceived as a coordinated, interrelated, interdisciplinary set of projects. Over the past several years, HURTC research efforts have focused on a variety of issues including: the prevalence and distribution of disabilities, variables that influence employment outcomes, and variables related to the cost of purchased services relative to the needs of persons with disabilities from diverse ethnic backgrounds. The following discussion provides highlights from three research efforts that have been undertaken by HURTC.

Prevalence of Disabling Conditions Among Diverse Racial/Ethnic Groups in the United States

Minority people with disabilities continue to represent a substantial proportion of the population with disabilities. The objectives of the study were to:

- compare specific disability rates among racial/ethnic minority populations compared to whites,
- state the specific disability rates for racial/ethnic groups according to geographic region,
- document specific disability rates for several types of disability among racial/ethnic groups in the United States, and
- identify the relationship among the specific types of disability and demographic characteristics such as age, family, income, sex, marital status, education, employment, and geographic location.

The primary data source for this study was the *National Health Interview Survey*, conducted by the National Center for Health Statistics (NCHS). The sampling procedure was multistage and based on primary sampling units selected in such a way as to ensure accurate representativeness. The sample for the study was comprised of 120,032 people who had been interviewed from 46,761 households in 1991.

The findings note that significant variations exist within the area of chronic health conditions relative to gender. The overrepresentation of African Americans and Hispanic Americans in all disability categories—chronic health conditions, physical, sensory, and language impairments, and nervous and mental disorders—indicates that whites are generally healthier than minority groups. In general, whites have lower rates of disability and are generally healthier than persons from other racial/ethnic groups. Significant variations exist within the area of chronic health conditions relative to gender. African Americans had the largest male/female percentage difference (38.68 percent male; 61.32 percent female) among all four of the

racial/ethnic groups compared. African American females have disproportionately high rates of arthritis, hypertension, diabetes, and heart disease. Similarly, Hispanic females also had a higher share of arthritis, hypertension, heart disease, and diabetes. Among persons with mental and nervous disorders, African American males represented higher percentages compared to the general population. In all categories of disabilities, a majority of persons were in the age groups between 17 and 64. Other notable findings relative to age and disability are: While only 9 percent of whites under 16 years had "other psychosis," 46 percent of Hispanics, and 20 percent of African Americans in this age group fall into this category. Similarly, exceptionally high percentages of African Americans and Hispanics with mental retardation were under 16 years of age. In addition, slightly more than half of all persons with epilepsy were under 16 years of age. Two major conclusions that emerge from these findings are:

- A large number of minority persons with disabilities are in the working-age population.
- Disproportionately high numbers of African Americans and Hispanic persons especially at a very young age seem to have nervous disorders and mental health challenges.

HURTC conducted an earlier study to examine the prevalence of disability (Asbury et al., 1991) among racial/ethnic minorities. Data for this earlier study came mainly from the 1987 *National Health Interview Survey* (NHIS). The authors of the earlier study had drawn special attention to the disproportionately large number of young African Americans and Hispanics in the mental retardation and nervous disorder groups. Findings from the more recent survey (Walker, et al., in press) reveal strikingly similar results indicating very little change in the disability conditions across racial/ethnic groups based on an analysis of 1987 and 1991 NHIS data. The earlier study highlighted the possible connection between the overrepresentation of African Americans in special education classes in public schools and the overrepresentation of African Americans under age 16 in the mental disorder and nervous disorder groups. This overrepresentation was also attributed to the likelihood of lower educational attainment among persons from minority groups. The findings of the more recent study concur with the above mentioned assumptions and require an investigation of why young persons from minority groups are susceptible to certain mental and nervous disorders.

As was observed in the prior study, there is a remarkable consistent tendency for minority persons across disability categories to be at the bottom of the economic ladder and for whites to be at the top. Table 1 describes the median incomes for each racial/ethnic group across the four disability categories.

A comparison between 1987 and 1991 median family incomes across racial/ethnic groups reveals two very striking similarities about the relationship between race/ethnicity and family income. First, the four racial/ethnic groups are in the same relative income position, no matter what disability category, with whites consistently at the top and African Americans consistently at the bottom. Additionally, it is noteworthy that the income increases for African Americans and Hispanics over 5 years were quite marginal compared to the income increases realized by whites during this period. This finding leads us to conclude that African Americans and Hispanics with disabilities have not only lower incomes compared to white persons with disabilities, but they also appear to receive incomes not commensurate with the rising costs of living. The findings in this study indicate that African Americans were underrepresented among those who were married and living with a spouse and

Table 1
Median Family Income by Race/Ethnic Group in 1987 and 1991

Disabling Conditions	Median Family Income							
	Whites		African Americans		Hispanic Americans		Overall	
	1987	1991	1987	1991	1987	1991	1987	1991
Chronic Health Disorders	19,000	22,577	10,000	11,235	13,000	15,209	17,500	21,233
Physical, Sensory, Language Impairments	22,050	26,014	10,800	14,055	16,500	18,652	20,000	21,980
Nervous Disorders	18,000	22,330	9,500	11,024	13,250	16,152	16,250	21,700
Mental Disorders	16,600	17,713	10,000	11,493	13,500	11,147	14,121	15,712

overrepresented among those who were widowed, divorced, separated, or never married. Compared to whites, minority persons were proportionately fewer among those who were married and living with a spouse. A point worth noting is that the proportion of never married persons was particularly high among those who had mental or nervous disorders.

With regard to employment, although persons in all racial/ethnic groups were largely in the working age category, only a small segment were employed. In three of the four disability categories, African Americans had the highest proportion of persons who were not in the labor force. Hispanics were also hard hit by unemployment. The question of why a substantial number of working age persons with disabilities are unemployed is worth probing. Earlier studies have pointed to factors such as accessibility and job accommodation issues, Social Security Insurance (SSI), and Social Security Disability Insurance (SSDI) as reasons for persons with disabilities not being in the labor force.

The above findings give strong evidence that minority persons with disabilities are at a substantial disadvantage with regard to poor health status, low income, and unemployment. A lack of equal opportunity, in the true spirit of the term, may well be a strong reason for the present status of minority persons with disabilities. At the present time, when policies are being overhauled and more powers and monies are being shifted to state and local authorities, it is crucial that persons with disabilities, especially those from minority groups, get more opportunities and appropriate services to benefit themselves and the nation.

An Examination of Variables Relative to the Cost of Purchased Rehabilitation Services

A 1993 report of the General Accounting Office (GAO) identified differences in the amount of purchased services dollars that vocational reha-

bilitation (VR) agencies spent on white Americans in comparison to individuals from various racial/ethnic minority populations. The findings were obtained from the *Rehabilitation Services Administration Case Services Report* (Reported on RSA 911). Specifically, the report suggested some variations in delivery of services and cost among various groups. In light of the findings by GAO indicating racial/ethnic variations, HURTC conducted a followup study to continue the analysis. The primary objectives were to verify the existence of such variations and to determine the extent and source of these differences.

A lack of equal opportunity, in the true spirit of the term, may well be a strong reason for the present status of minority persons with disabilities.

The data analyzed in this study consisted of 202,479 clients representing the nation's population of clients across all agencies, regions, and racial/ethnic groups who received vocational rehabilitation in 1991. Many of the initial analyses for this study, including some of the cross-tabulation analyses, were conducted on the population database to obtain descriptive profiles on important variables such as race/ethnicity, major disability, cost of purchased services, and the interrelationships among them. In addition, some of the populations were useful in addressing the research questions. However, for most of the analyses, a sample of 28,138

clients was randomly selected. A major selection criterion was closure status of clients who had completed the program. With the exception of American Indians and Asian Americans, who were too few to sample, all other racial groups were randomly represented in the sample. (All cases for American Indians and Asian Americans were included in the analysis.)

As a starting point for understanding the cost of services for each racial/ethnic group, it was first determined that the distribution of groups was 72.4 percent for whites, 17.5 percent for African Americans, 62 percent for Native Americans, 1.04 percent for Asians, and 8.4 percent for Hispanics. These data were important since they represented a standard for determining over- or underrepresentation of groups in various categories, (e.g., cost categories).

The research questions, which provided the framework for the study were conceptualized into three major sets of analyses:

- those pertaining to cost of services,
- those pertaining to racial/ethnic differences and process activities, and
- those pertaining to outcome.

Outlined below are the major findings relevant to each of the three sets of analyses.

Major Findings for Cost of Service

In general, the findings confirmed the presence of racial/ethnic differences in cost of client services for the 1991 program: white clients tended to have more money spent on their program services than did other groups. The findings from the analysis also demonstrated that Asian clients may have had slightly more money spent on their services compared to other minority groups. Although the pattern did vary somewhat by the region of the country, being African American, Hispanic, or American Indian was typically not so positive as being white or Asian when it came to monies spent.

However, it was noted that the extent of the race/ethnicity effect, although significant, tended to be rela-

tively small in comparison to other factors, such as time in the VR program, number of services provided, and the type of disability.

Time in VR and number of services were consistently found to be the best predictors of cost of purchased services across the nation, across the regions, and across almost all of the disabilities analyses. But it is also noteworthy that none of the prediction equations accounted for more than half of the variance in cost of services. A clear pattern emerged indicating that major disabilities pertaining to major physical and sensory conditions (e.g., orthopedic conditions and blindness) tended to be associated with higher client cost than disabilities involving more mental health and social disorders (e.g., drug abuse, mental retardation, and psychotic disorders).

Across the various disability groups within the 10 different regions, race/ethnic membership was a significant predictor of the cost of purchased services about 10 percent of the time; but in general, the effect size was small. Within the framework of a race/ethnicity effect, whites and Asians appeared to have had more money spent on them when it came to cost of purchased services; but there was some evidence at the national and regional levels to suggest the problem was concentrated in disabilities, such as drug abuse and mental retardation. That is, racial/ethnic differences were rarely found for clients with physical and sensory disabilities such as orthopedic conditions and blindness. The racial/ethnic effects were particularly apparent in several of the agency analyses for both physical and mental disabilities alike. In addition, those effects tended to be larger, but not necessarily always in favor of a particular racial group.

Major Findings for Process Activities

In general, little evidence for differences in services provided emerged from the findings. No substantial differences in type of services provided were noted for the various racial/eth-

nic categories of clients. Clients who received transportation services, adjustment training, and on-the-job training outside of the agency tended to have higher weekly earnings at the end of the program; however, whether such training was received inhouse or not did not vary by the racial/ethnic membership of the client.

Source of transportation was the strongest predictor variable in this study and appeared to carry more weight than psychological factors in understanding employment outcome.

Major Findings for Outcome Measures

In general, the outcome analysis revealed that "success" most notably, as defined by more weekly earnings and work status at closure, was associated with economic characteristics of the client during the course of the program. Clients with higher educational levels and more economic independence at program entry had higher weekly earnings at closure and had more services provided to them during the program. Employed clients had slightly more money spent on them during the program than unemployed clients.

The findings indicate that time in the VR program, number of services provided, and the type of disability were the most significant factors affecting cost of services for the 1991 clients. However, the data also confirmed the presence of race/ethnicity effects at the national, regional, and agency levels. Such findings, although generally small in

their overall effect size, were consistent and statistically significant. The problem appeared to be more prevalent among cognitive and mental health impairments as opposed to physical disabilities in favor of whites and Asians at the national and regional levels.

There was little evidence that the program activities varied by racial/ethnic category, but clearly some of the services (e.g., outside transportation) were more likely to be associated with positive outcomes than others.

In the final analysis though, the more educated, economically independent clients who received more services and had more money being spent on them had a higher probability of positive program outcomes (e.g., employment status and earnings). Such clients tended to be white and Asians.

Predictors of Employment Outcome of African Americans with Disabilities

(Belgrave and Walker, 1991)

A study was conducted to determine variables attributed to the employment status of African Americans with disabilities. The sample consisted of 75 African Americans between the ages of 18 and 45 (males, 60 percent; females, 40 percent). A larger percentage of employed than nonemployed subjects owned their own transportation (63 percent versus 30 percent) and were better educated (85 percent of the employed group versus 67 percent of the unemployed group were high school graduates). A discriminant analysis was computed to (a) identify variables that best discriminated between the employed group and the nonemployed group, and (b) to determine the total amount of variance in employment outcome that could be accounted for by the variables used in this study. Transportation and social support were significant discriminating variables. Self-esteem and the subjects' influence on health outcomes were marginally significant in predicting employment outcomes.

Source of transportation was the strongest predictor variable in this study

and appeared to carry more weight than psychological factors in understanding employment outcome. These findings suggest that transportation status can be an important consideration when planning vocational rehabilitation programs for African Americans with disabilities. The availability of social support was also a significant factor in employment outcomes.

There are some limitations to the study's findings. The sample of African Americans used in this study is not representative of the population of African Americans with disabilities. Subjects in this study were younger, had slightly higher incomes, were better educated, and were more likely to be employed than subjects in the general African American disabled population. Subjects were also clients of participants at rehabilitation agencies or facilities. Many of the limitations of this study can be addressed by using a larger more representative sample of African Americans with disabilities. Cross-validation studies would also be useful to determine if these same variables predict employment outcomes for African Americans and other minority persons with disabilities.

Training Focus

A number of training and technical assistance models have been implemented by HURTC since 1988. These include the following:

- The *Minority Scholars Training Program*, which provides an opportunity for minority persons at the undergraduate level to develop and enhance their leadership, research, and technical skills to serve persons with disabilities and their families more effectively.

- The *Bridges to Leadership 2000 Youth Mentorship Program*, which is designed for low income students with disabilities from diverse racial/ethnic backgrounds who are enrolled in schools in the Washington, DC, Metropolitan Area and other selected locations in the United States to help them formulate and subsequently attain career and employment goals.

- The *Rehabilitation Research Technical Assistance and Mentorship Model*: HURTC provides technical assistance to historically black colleges, minority institutions of higher education, and other organizations in order to facilitate the development of research, leadership, and training capabilities relative to the needs of persons with disabilities from multicultural communities.

- The *Family Outreach Program*, whose outreach activities include empowering families from diverse racial/ethnic populations to take advantage of rehabilitation and related services as well as enhancing the service delivery systems.

Two HURTC training models are described below.

Minority Scholars Training Model

NIDRR has substantiated the need to increase the number of minority persons in leadership positions in the rehabilitation system. The purpose of the *Minority Scholars Training Model* is to provide an opportunity for minority persons to develop and enhance their leadership, research, and training skills to more effectively serve persons with disabilities and their families. The program provides opportunities for undergraduate and graduate students with disabilities. The primary goals of this project are:

- to implement a minority scholars model, which prepares students from diverse backgrounds to work with individuals with disabilities and their families; and

- to provide a vehicle which will expose trainees to a wide range of research experiences and community resources; facilitate student interaction with professionals from various community-based agencies, and enhance the professional growth and development of program participants.

During the last 7 years, seven undergraduate students with a variety of disabilities have participated in the program. Well over 40 graduate students have successfully participated in this unique program. Trainees are exposed

to a variety of experiences, including participation in various research studies; the development of training and resource materials; site visits to governmental agencies; interaction with professionals, including persons with disabilities and advocates; and participation in conferences, workshops, and seminars. Graduates serve in a variety of capacities such as school psychologists, special education teachers, mental health professionals, researchers, and rehabilitation faculty in various colleges and universities throughout the country.


Bridges to Leadership 2000: Youth Training Model

There is a dire need for programs that facilitate the transition of minority youth with disabilities from school to work and postsecondary educational settings. Because a large proportion of minority students come from low socioeconomic backgrounds, they are less likely than other students to have role models, work experience opportunities, and linkages to the world of work. The purpose of this training project is to assist low income and minority students enrolled in middle and high schools in the Washington, DC, area and in other select geographic locations in the United States to formulate career goals and subsequently obtain employment.

The *Bridges to Youth Leadership 2000 Minority Students with Disabilities Mentorship Program* seeks to fulfill the need to help low income and minority youth with disabilities in their transition experience, by offering role models, work experiences, and linkages to the world of work and postsecondary educational settings. The program seeks to meet the student at the transitional stage (ages 11–21) while the transition process is taking place.

This program receives support from a wide cross section of individuals and organizations. In Washington, DC, youth leadership meetings take place on the first Friday of every month; special events are organized on several Saturdays during the project year. The

program provides knowledge about the world of work, self-confidence and social skills. Various activities include children with disabilities as well as those without disabilities. The project is being carried out in the District of Columbia, New Jersey, Michigan, Georgia, New York, California, Oregon, and Louisiana. A *Career Day Conference* and a *Special Achievement Incentives Contest* are implemented on an annual basis in participating cities.

A unique feature of HURTC is the interface, collaboration, and networking of Howard University units, federal and state rehabilitation agencies, private agencies, other research and training centers, the corporate sector, and people with disabilities throughout the United States. 

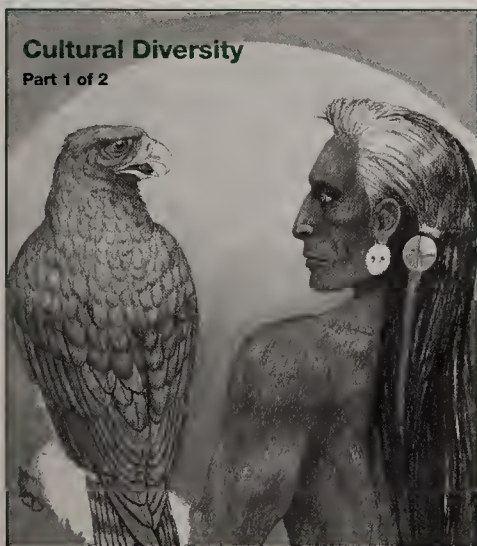
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AMERICAN REHABILITATION Spring 1996

Cultural Diversity Part 1 of 2



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Closing the Shop: Conversion from Sheltered to Integrated Work

A book review

Judith E. Heumann

There is probably no group in the United States more in need of the provision of timely, well-planned, and effective rehabilitation and employment services than the 69 percent of unemployed people with disabilities who are of working age. By contrast, only 19.7 percent of people without disabilities are unemployed. Discrimination is often a significant part of the lives of people with disabilities, and physical, psychological, social, and attitudinal barriers abound. All of these factors can effectively stifle equal opportunities and preclude the ability to strive for independence for many people with disabilities in the United States.

To help lower the historically high unemployment rate for people with disabilities, various strategies for achieving successful employment outcomes have been developed:

- the state-federal vocational rehabilitation (VR) program, which is aimed at achieving integrated employment through a variety of rehabilitation strategies;
- sheltered employment; and
- supported employment with its various models.

Sheltered employment was developed when there were no laws prohibiting discrimination against individuals with disabilities in the employment market and when adults with disabilities who wanted to enter the employment arena were excluded. Sheltered workshops, like most segregated education pro-

grams, were a way to prove that people with disabilities could indeed work and learn. Sheltered programs were not envisioned to develop into industries that precluded people with disabilities from being integrated into society and all facets of community life. If we had believed in the past what we believe today—that people with significant disabilities can work in integrated settings with appropriate supports—sheltered workshops might never have evolved. Now we are in the position of having to convert sheltered programs to reflect more modern thinking.

Options in this regard have met with varying degrees of success over time, and no one option is right for everyone. There has long been a debate in the rehabilitation community regarding the value of sheltered employment versus that of integrated employment. Some people believe that sheltered employment perpetuates “institutionalized behavior” on the part of people with disabilities, but others believe that a positive sheltered work experience is better than no work experience at all. In terms of integrated employment, many proponents believe that individuals who have been mainstreamed improve their occupational success rates because they have typical citizens as their role models.

This leads purportedly to more “normalized” work behaviors and fuller integration into the community. Additionally, professionals in the rehabilitation community have stated that because more and more individuals with severe disabilities have been mainstreamed during their years in school, they are consequently much better prepared for integrated employment.

Given the imperfections that exist in our society, there may be truth in both




Judith E. Heumann, Assistant Secretary, Office of Special Education and Rehabilitative Services, U.S. Department of Education

points of view. *Closing the Shop*, then, adds yet another chapter to this complex and important inquiry, examining all aspects of the issues involving agency conversion from sheltered to integrated employment models.

This book accepts the premise that with the right tools and the right knowledge, many sheltered settings can undergo a process of conversion that will allow them to offer the same level of support in a more integrated environment. The concept of conversion involves restructuring a rehabilitation agency's program and changing its focus from segregated, sheltered employment to mainstream, integrated employment—a complex and difficult process.

Among the issues involved for a non-profit agency to convert or restructure the way in which its programs operate are:

- retraining staff regarding a new way of providing services for individuals with disabilities in work settings, and
- recognizing the accompanying need to be sensitive to a business' needs. Also, funding issues are significant to nonprofit agencies as they undertake conversion, in that funding sources are often different or nonexistent for integrated employment programs. In addition, the work in integrated settings is more labor intensive and individualized and is likely to be more costly. Furthermore, the management aspects of dealing with staff who are based in a multitude of locations with a myriad of competing problems is a challenge to nonprofit agency managers and supervisors.

This book addresses actual examples of agency conversion and documents the experiences of people with disabilities and other stakeholders during the conversion process. Certainly, in applying the material contained in this book to the variety of specific settings that now exist, its precepts and methods will be useful to some and breakthrough experiences for others. 


Closing the Shop (1995). Stephen T. Murphy and Patricia M. Rogan. Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624. 221 pages. Softcover, \$26.

RSA's Capacity Building

(Continued from inside front cover)

- Assumption College, Worcester, MA;
- Children's Hospital, Boston, MA;
- Florida A&M University, Tallahassee, FL;
- George Washington University, Washington, DC;
- Howard University, Washington, DC;
- Jackson State University, Jackson, MS;
- Langston University, Langston, OK;
- New Mexico Highlands University, Las Vegas, NM;
- Northern View A&M University, Prairie View, TX;
- Salish Kootenai College, Pablo, MT;
- San Diego State University, San Diego, CA;
- Southern University, Baton Rouge, LA;
- State of Hawaii, Division of Vocational Rehabilitation, Honolulu, HI;
- University of Arkansas at Pinebluff, AR; and
- Urban League of Northeastern New York, Albany, NY.

These organizations will work collaboratively to reach as many as possible of the entities identified in Section 21 of the 1992 amendments during the 3-year project life.

The capacity building activities which will be carried out by the grantees include proposal development, grant writing workshops, grant management seminars, and organizational development programs. Technical assistance concerning funding competitions will also be offered to organizations seeking to participate in funding competitions. Information concerning the scope of work which is being undertaken by each of the projects can be obtained by contacting the project directly or by calling Ms. Ellen Chesley at RSA. 



Hotline on Blindness

The American Foundation for the Blind (AFB) operates a toll-free telephone hotline to answer all questions about blindness as well as providing information on services, technology, publications, and consumer products available to blind and visually impaired people.

The AFB hotline, 1-800-232-5463, is in operation from 8:30 a.m to 4:30 p.m. Eastern Standard or Eastern Daylight Time, Monday through Friday. Calls to the hotline can be made from anywhere in the continental United States, but New York residents should use (212) 620-2147.



Audio Cassettes of AR

Taped Copies of American Rehabilitation are available to blind and physically handicapped persons through local regional offices under the National Library Service for the Blind and Physically Handicapped. Contact your public library for the location of the regional library which serves your state.

NEW PUBLICATIONS AND FILMS

The Encounter.

Produced by Richard Mettler, State of Nebraska Department of Public Institutions, Division of Rehabilitation Services for the Visually Impaired. Available from Carmichael Audio-Video, 1025 South Saddle Creek Road, Omaha, NE 68106. Telephone, (402) 556-5677. VHS videotape, \$8.50.

This public service animated video is available as a disability awareness tool which advocates full inclusion in society. Also available in a Spanish language version entitled *El Encuentro*, this video tells a humorous story where a perplexed sighted pedestrian asks a book salesman, "What are you supposed to do when you meet a blind person?" The salesman uses this confusion to fool the man into buying a useless book called *Advice for All Occasions*. During their conversation, a variety of myths and misconceptions about vision loss are exposed as being silly. Nonetheless, it is this kind of misunderstanding that prevents fair opportunities in the mainstream of community life, including school and the workplace.

The Encounter explains that there is no special advice for getting along with blind people beyond what works with anyone else, and that once sighted people understand this they can relax in their interactions with blind persons and be guided by their common sense knowledge of how all people enjoy being treated.

The President's Committee on Employment of People with Disabilities presented *The Encounter* with the 1992 Media Award for the single best public service production in the nation. The President's Committee recognized *The Encounter* as capturing the essence of the Americans with Disabilities Act, which asks only that disabled people have a

fair opportunity to participate fully in the life of the community. The attitude communicated in this video is beneficial to all citizens, regardless of disability.

The Encounter has been used by hundreds of agencies and organizations and viewed by thousands of persons in the United States and in other countries for personnel training and public service activities locally and by public school systems, human service agencies, hospitals, and nursing homes. It has also been aired on television on numerous occasions, including a nationwide broadcast by the Public Broadcasting Service to all 340 of PBS's affiliate stations.

The Ultimate Disability Handbook.

Allison Rutland Soulen, Esq., and S. Joseph Fleres. Fleres and Soulen Publications, 5565 Columbia Pike, Suite 211, Arlington, VA 22204. Softcover, 67 pages. \$19.95 plus shipping and handling. Also available as audio cassette for \$24.95 plus shipping and handling.

Written primarily for the layman, this book is also a useful guide for lawyers, physicians, and other professionals who have not dealt with problems encountered in helping persons with disabilities apply for Social Security and Workers' Compensation benefits.

This publication is intended as a guide and reference on how to deal with the bureaucratic maze for persons with disability who are eligible to receive benefits.

The authors are well qualified to lend their expertise and guidance on this subject. Ms. Soulen is an attorney in Washington, DC, who represents clients with disability claims before the Social Security Administration. Mr. Fleres is a paralegal with 15 years of ex-

perience in the area of disability benefits, including lecturing in public seminars and law schools.

Cognitive Learning Theory and Cane Travel Instructions: A New Paradigm.

Richard Mettler. State Of Nebraska, Department of Public Institutions, Division of Rehabilitation Services for the Visually Impaired, 4600 Valley Road, Lincoln, Nebraska 68510-4844. 170 pages. \$10.00 (Make checks payable to: Rehabilitation Services for the Visually Impaired.)

This treatise advances an alternative approach to the training of cane travel instructors. The training model used is grounded in what is termed "structured discovery learning." Recent developments in cognitive learning theory are applied to explain a way to teach cane travel which is in dramatic contrast to the teaching model which appears to currently dominate the field. By changing the focus from what the instructor knows to how the student learns, this book offers a new paradigm for understanding all aspects of the psychomotor skill of cane travel. The book argues that superior cane travel instruction results from cultivating the perceptual, cognitive, and motor skills of cane travel from within the student's immediate experience and within the student's locus of control. A second practical benefit from this new paradigm is a way to relieve this country's severe and longstanding shortage of rehabilitation professionals capable of teaching cane travel—resulting in large and growing numbers of underserved and unserved blind persons. The structured discovery teaching model for cane travel instructor training can easily be conducted at the local agency level, or at an educational institution—university,

college, or community college—and can be completed in 3 months. This training is appropriate for orientation and mobility specialists interested in expanding their teaching repertoire, rehabilitation teachers who wish to add travel instruction to their areas of service delivery, and newly-hired preservice agency personnel who will likely be in a position to teach cane travel.

Implementation of a New Model for the Randolph-Sheppard Program in Florida: Findings and Recommendations.

J. Elton Moore, Ed.D., Brenda Cavenaugh, and John H. Maxson. *RRTC on Blindness and Low Vision*, P.O. Drawer 6189, Mississippi State, MS, 39762. Softcover, 90 pages. \$20.00.

This report focuses on developing a comprehensive training program for new and existing facility managers, contracting with a Nominee agency to manage selected SLA program functions and developing operational standards for the EATZ program, a concept designed to provide a standardized format for various food service operations.

Substance Abuse and Physical Disability.

Allen W. Heinemann, editor. *The Haworth Press, Inc.*, 10 Alice Street, Binghamton, NY 13904-1580. 289 pages. Hardcover, \$44.95; softcover, \$32.95.

Alcohol and drug abuse is a contributing factor in traumatic and disabling injuries as often as 62 percent of the time. Until now, there has been virtually no literature available on physical disability and substance abuse. This book brings together these topics in an effort to provide readers with the vital information necessary to understand the significant challenges, risks, and threats that substance abuse and chemical dependency pose for people who are physically disabled.

Designed to provide the materials needed by professionals to understand the context of substance abuse in the lives of persons with disabilities, identify chemical dependency problems, and im-

plement effective treatment strategies, the book is divided into three sections:

- discussing the context, issues, and problems of substance abuse;
- causes, types, and prevalence of substance abuse; and
- assessment, treatment, and prevention issues.

Coverage includes chapters addressing medical complications and prescription medication issues in rehabilitation, pain management, consequences of alcohol and drug problems following physical disability, and a review of assessment and treatment issues to help rehabilitation workers select chemical dependency treatment programs.

Encyclopedia of Disability and Rehabilitation.

Arthur E. Dell Orto and Robert P. Marinelli, editors. *Macmillan Library Reference*, Attn: Kristen Max, 866 Third Avenue, 2nd Floor, New York, NY 10022. Toll-free number: 1-800-223-2336. 800 pages. Hard cover, \$105 plus \$4 for shipping.

Organized in this one volume are 159 articles on specialized subjects, written by experts in the field of disability and rehabilitation and covering all kinds of disability, ranging from physical and mental to organic and traumatic.

This comprehensive reference work should help considerably in the understanding of disabilities and the rehabilitation process by providing relevant information on a vast range of disabilities and available therapies, processes, concepts, and sources of support for people with disabilities and their families, coworkers, caregivers, and interested laypersons.

Arranged alphabetically and fully cross-referenced, this book allows the user to find other entries related to the original topic of interest. Some articles also include lists of organizations and foundations as resources for help or for further information.

Motor Speech Disorder: Advances in Assessment and Treatment.

James A. Till, Kathryn M. Yorkston, and David R. Beukelman, editors. Paul H.

Brookes Publishing Co., Inc., P.O. Box 10624, Baltimore, MD 21285-0624. 260 pages. Hardcover, \$38.

Based on selected papers given at the Conference on Motor Speech Disorders held in 1992 at Boulder, Colorado, this book reflects changes in perspective and advances in knowledge regarding motor speech disorders. Increased accessibility of computers and instrumentation has generated new diagnostic and treatment protocols; consequently, fewer practitioners rely on the ear alone for diagnostic assessment and scientific study. Furthermore, classification or labeling of persons with motor speech disorders is not seen as the end point of evaluation; rather, researchers are looking beyond medical diagnosis to classify dysarthric individuals for group comparisons. Also, there is increased interest in quantifying functional aspects of the disordered speech related to intelligibility, speech naturalness, and even individuals attitudes about themselves and their communicative interactions.

Assistive Technology: A Resource for School, Work, and Community.

Karen F. Flippo, Katherine J. Inge, and J. Michael Barcus, editors. Paul H. Brookes Publishing Co., Inc., P.O. Box 10624, Baltimore, MD 21285-0624. 272 pages. Softcover, \$34.

This book brings together a number of nationally recognized authors who discuss the application of assistive technology in various environments: school, work, and community. Each chapter focuses on the need to place the user of technology at the center of design, training, and the implementation process. Case studies demonstrate assistive technology in action, and resource lists guide the reader to particular devices and information. Finally, descriptions of innovative loan programs and other funding options are provided to help users and professionals design strategies for gaining access to technology

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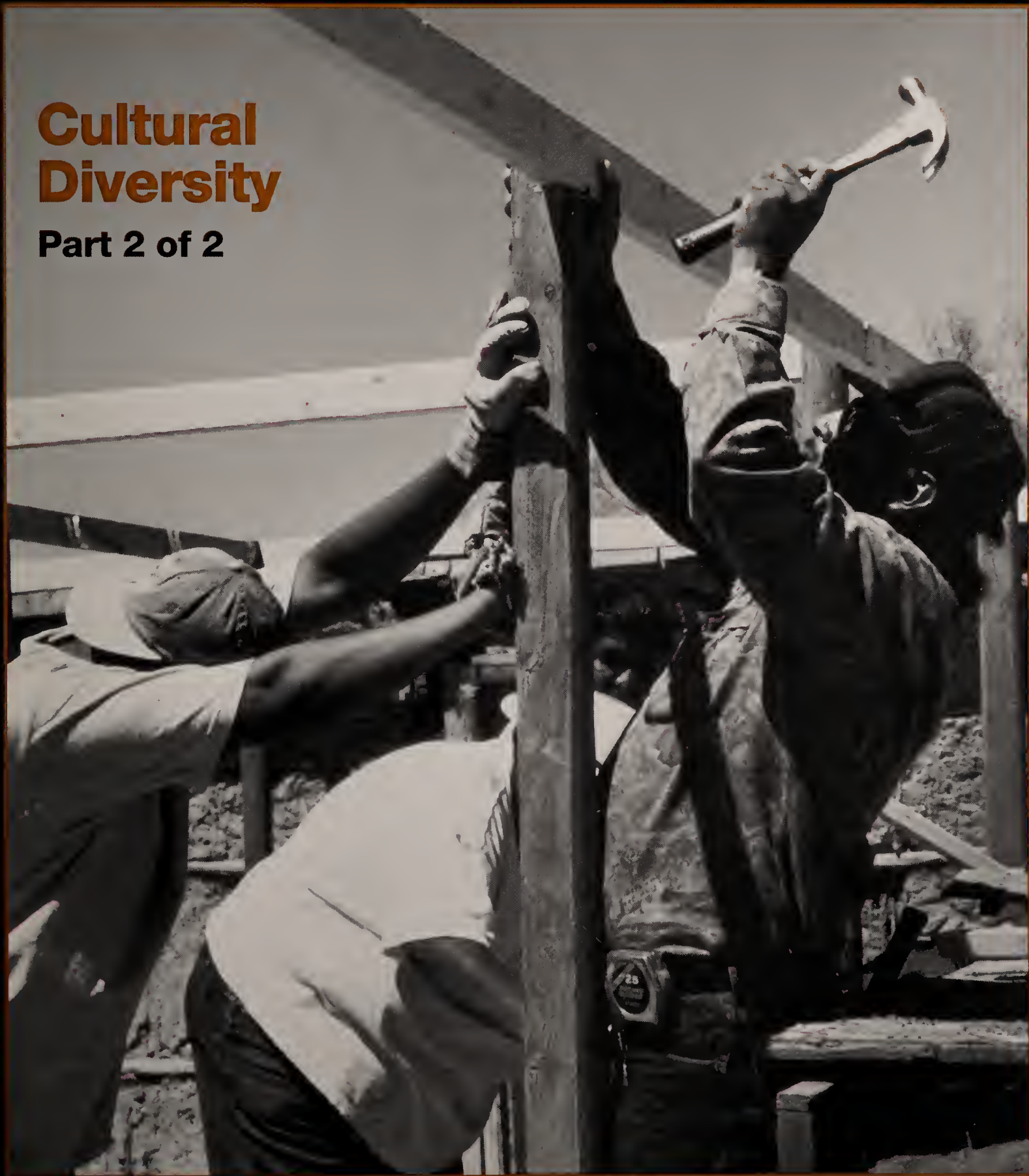
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AMERICAN REHABILITATION

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U.S. DEPARTMENT OF EDUCATION
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Walking in Two Worlds: Native Americans and the VR System

This article, especially the introduction, presents to the reader an overview of American Indian life to assist the vocational rehabilitation (VR) counselor in understanding the Indian VR client. No one article can contain particulars for each individual tribe; the statements made here are designed to be descriptive of the majority of the Indian population that VR counselors might encounter. The terms American Indian and Native American are used interchangeably.

Carol Locust, Ph.D.
Jerry Lang

Introduction

Walking in two worlds, the American Indian world and the non-Indian world, is a phrase that describes almost every American Indian life. Sometimes the two worlds clash, sometimes they can be harmonious but, for the most part, walking between them requires a balancing act of cultures. Within the Indian world there are many tribes, the members of which cope daily with the two-world environment in which they live. Each tribe is a separate entity and as such has its own traditions, culture, language, lifestyle, and spiritual values. Despite the diversity among tribes, however, there are many experiences and reactions to outside culture domination that are common to all tribes. Results of the common experiences and reactions have been called "post colonization stress disorder" (PCSD), a set of behaviors and attitudes that indicate physical, psychosocial, and spiritual declines that seem epidemic among Indian people nationwide. Common physical problems related to PCSD are poor health and chronic disability, poor nutrition, alcoholism and drug dependency, and staggering rates of diabetes. Environmental problems include substandard housing, poor sanitation, unsafe and unreliable water supplies, unimproved roads, and isolation in rural/remote areas (NAU-UA, 1987). Many of the problems listed here appear to be the result of abject poverty, poor oversight of treaty rights by the U.S. Government, loss of hope, feel-

ings of being helpless, of shattered cultures and religions, unabated grief, and depression: characteristics that are commonly found among prisoners of war. Excellent reading on these topics are Vine Deloria Jr.'s book, *Custer Died For Your Sins* (1970), and Angie Debo's *Aud Still The Waters Run* (1940).

For an American Indian, the preferred status of many is to be a full blood Indian of one tribe, come from a reservation, know your culture, and speak your language. However, if an Indian is full blood and comes from a reservation, chances are that he or she will come from an environment very similar to that described above. Also, the boarding school may have been his educational environment, an atmosphere that was not conducive to native cultural preservation. Boarding school educations stripped many tribes of their language by forcing the English language upon the children. The boarding schools were said to educate the Indians, but many Indians believe the real purpose was to sever the ties between children and their language and culture. Certainly the education was poor, often carried out in prison-like systems, where corporal punishment was used frequently and speaking your own language often brought dire results.

Half bloods truly have a foot in each world. They often endure the "neither" experience; being neither Indian nor white, not really accepted by either, but

Dr. Locust is the Director of Training at the Native American Research and Training Center, University of Arizona, Tucson, and Mr. Lang is a program manager for Native American Programs, Division of Vocational Rehabilitation, Tallahassee, Florida.

yet part of both. Half bloods hear "He's half white" as a derogatory statement from Indians, and "He's half Indian" from non-Indians. Quarter bloods have the advantage of being more in the "favored" class of American society (being mostly white), but the advantages become disadvantages in the Indian world if the quarter blood has fair hair and light eyes. Many of the quarter bloods choose the non-Indian path, but many cling to the Indian way, where their physical appearance may create problems.

Mixed bloods are a diverse group; some of them may choose not to admit their Indian heritage while others hold it close in their hearts. Those that are involved in the Indian world are often fiercely proud of their heritage and are easily offended if they think they are classed as a *wannabe*: a non-Indian who wants to be Indian and whose "great-grandmother was a real Indian Princess." Other *wannabe* names are "fake," "plastic," or "New-Age" Indians; often they steal and then prostitute traditional ceremonies, sell seats at sweats or ceremonies for cash, or copy spiritual rituals for their own gain.

There is another facet of the Indian picture that state VR counselors may have to deal with, a group who call themselves *Split Feathers*. These are adult Indians who, in childhood, were removed from the tribes and placed in white homes. The removal split them between their two cultures, thus the name, *Split Feathers*. The adults in this group are likely to have a lot of anger and frustration, feelings of being betrayed, being a "nobody," and they often abuse alcohol or drugs. "I don't know who I am" is a frequent statement, many saying they do not even know what tribe they come from. In a recent study (Locust, 1994), the majority of *Split Feathers* who responded to a national survey noted that they had failed in school, had problems with employment, had alcohol problems, were anti-social, and felt that they didn't belong anywhere. The pain caused by the loss of their culture was overwhelming; it is no wonder that many of them reported having been in jail or prison. A state counselor attempting to work with a



Pow-wow photo, Tucson, 1984

Being Indian is in your heart . . . if I maintain the old ways and honor my heritage, I know who and what I am.

Split Feather needs to understand the pain and to help the person heal inside as a first step toward employment.

Sometimes the pain an Indian suffers—because of historical events that render his/her personal identity incomplete and fragmented in terms of heritage and culture—leaves its mark in rage and depression. These feelings were well stated by one participant of a workshop on American Indian and the Vocational Rehabilitation Services held in Florida (Locust, 1992): “Indianness is in your heart, not in the color of your skin or the shape of your nose. Tribal groups, especially the smaller tribes and splinter groups, were near extinction, and marrying a non-Indian may have been the only solution to prevent genocide. That created half-bloods, and from then on the blood quantum fluctuated according to whether there was someone from your tribe that was marriageable. Tribes were forced into those situations, they did not choose it. Now we, the descendants, are penalized for those choices. Mixed bloods are suspect and degraded by whites and Indians alike, but if I walk the *Old Way*, if I maintain my heritage in my heart and my life, I know what I am on the inside.”

The historical and current status of American Indians is hurtful and depressing not only for the people who live it, but for the non-Indians who sympathize with them. However, there are strengths in Indian cultures that have persisted over the decades. One of them is the innate spiritual beliefs that have survived despite religious persecution and repression. The 10 points that follow appear to be the founda-

tion on which many tribal religions and philosophies are based, although each tribe is distinct and different from other tribes and each group has its own way of expressing its beliefs. There is no set of beliefs that can be said as absolutes for all Indian cultures, as time and outside influences have changed things, but the 10 concepts are common to most tribal groups.

1. American Indians have a belief in a Supreme Creator. In this belief system are lesser beings also.

2. Man is a three-fold being made up of a body, mind, and spirit.

3. Plants and animals, like humans, are part of the spirit world. The spirit world exists side-by-side and intermingled with the physical world.

4. The spirit existed before it came into a physical body and will exist after the body dies.

5. Illness affects the mind and spirit as well as the body.

6. Wellness is harmony in body, mind, and spirit.

7. Unwellness is disharmony in body, mind, and spirit.

8. Natural unwellness is caused by the violation of a sacred or tribal taboo.

9. Unnatural unwellness is caused by witchcraft.

10. Each of us is responsible for his/her own wellness.

American Indian families also have something called *Standing Proud*: cultural values that have survived, or the tribes would have vanished long ago. *Standing Proud* has always been one of the American Indian's greatest strength. Each tribe has its own set of values that is regarded within that culture as desirable and fosters strength within an individual. The following list is a general overview of those values most likely to be found to some degree in the environments of urban and reservation Indians.

My family, clan, and tribe think well of me.

- I am sharing.
- I show concern for others.
- I help others.
- I protect those around me.
- I have respect for others.

I provide for my family, clan, and tribe.

- My family has food.
- My family has shelter.
- My family has clothing.
- My family has transportation.

I honor my ancestors by retaining the Old Ways.

- I participate in tribal ceremonies.
- I participate in tribal religious rituals.
- I maintain proper garments for ceremonies and rituals.
- I observe tribal customs.
- I contribute to the tribal ceremonies and rituals.

I do not seek to rise above others.

- I am not a showoff with what I have.
- I am not boastful of myself.
- I do not compete with others except in sports.
- I am not a know-it-all.

I walk in harmony with myself,

- my family,
- my clan,
- my tribe,
- my mother Earth,
- my universe,
- my Creator.

These are strengths that counselors can use to assist an Indian VR client. They are the basis of sound psychological wellness and personal power to overcome many of the characteristics of PCSD.

Vocational Rehabilitation Counselors and American Indians

State VR counselors are likely to have on their caseload at least one Native American who walks in two worlds. Because of that likelihood, the introduction to this article was included to provide the counselor a glimpse into the Indian part of the two worlds. The American Indians a counselor may come in contact with are likely to reflect the PCSD syndrome and the additional stress of urban life and unemployment, and also the internal strength of spiritual teachings and family values. Many rural/reservation Indians leave their homes where jobs are scarce for urban

Sometimes the pain an Indian suffers . . . leaves its mark in rage and depression.

areas where employment is more promising. While the job market is better, the cultural gap between Indians and non-Indians is often greater. Having a disability while trying to walk in two worlds can increase the stress tenfold. Having a counselor that understands PCSD, who is respectful of a client's heritage and culture, and who has the support and assistance of the VR administration is imperative for a successful VR closure on an American Indian (Locust, 1993).

If we look at the Indian issue from the other side of the fence, we find circumstances surrounding the VR counselor that frequently do not lend themselves to flexibility in terms of working with culturally diverse people. For example, if a counselor wished to observe courteous behaviors with an Indian client, the time spent with that one client would double or triple what might be necessary for other clients. Because of large caseloads, some counselors may not be able to do that, which means that they are seen as discourteous and rude to an Indian client who probably will not return, or that if they do follow traditional protocol, other clients may be cut short on time. For this reason, it is necessary that a counselor working with the Indian population have the full support and assistance of the VR administrative staff. It is ironic that none of the issues discussed in this article are new, as we can see from the following statement written nearly 20 years ago: "The greatest problems facing state Vocational Rehabilitation counselors in their efforts to improve services to Native Americans are that (1) the Native Americans come from different cultures from the counselors, and (2) most Native people live in rural/remote areas."

This statement was made in the 1978 *Annual Report of the Rehabilitation Services Administration* and ended with this comment: "If there is a single, important step that RSA should consider in order to improve VR services to Native Americans, that step is developing ways to take VR to the (reservation) Indians" (Schuurman, 1991).

Despite legislative and service delivery efforts, this statement is as valid



Workshop photo, Awkesasne Mohawk, 1992

Native Americans with disabilities often need someone from their own culture to advocate for them.

today as it was in 1978. While the statement indicates a concern for reservation Indians, it also has a bearing on urban Indians, because specific VR programs are provided for reservations but urban Indians must access state services. As of September 1, 1995, there were only 27 tribes (out of more than 500 recognized tribes/villages) that had VR programs (St. Clair, 1995). These 27 programs are part of Section 130 of Title I of the Rehabilitation Act and are commonly called Tribal 130 VR Programs. Section 130 was added to Title I despite language in Section 101 that addressed this issue: "... the State shall provide vocational rehabilitation services to handicapped American Indians resid-

ing in the State to the same extent as the State provides such services to other significant segments of the population of individuals with handicaps residing in the State."

The "to the same extent..." clause and Section 130 opened the door for expanded services to American Indians. However, the Section 130 Programs focus on tribal lands, while the "same extent" clause still covers the urban Indian populations.

Native Americans in the Vocational Rehabilitation System

Statistics on Native Americans as early as 1980 show that there is a trend away from reservation life to urban life. The 1980 U.S. Bureau of the Census reported that only 46 percent of American Indians lived in "identified Indian areas," leaving 54 percent that reside in rural/urban areas within state boundaries. The 1990 *Census* reported the total population of American Indians at 1.946 million, indicating that approximately 1 million American Indians are not served by Tribal 130 VR Programs

It is necessary that a counselor working with the Indian population have the full support and assistance of the VR administrative staff.

but fall within the work area of state vocational rehabilitation services. Of that million, we can expect that between 26.9 percent (Schacht, 1993) and 22.6 percent (Fowler, 1995) have a disability.

Despite the "same extent" clause, many states did not include American Indians when issues of diversity were discussed. In the 1980's, inclusion of Native people in VR services was overlooked in some states; considered not essential in others, because "We have no Indians in our state"; or the tribal people were still considered "wards of the government and, therefore, outside the responsibility of states" (Locust, 1988). None of the three reasons for non-inclusion are valid. How does a state *overlook* the indigenous citizens in its population? Would *ignore* come closer to the truth? The state that reported having "no Indians" in fact had *more than 35,000*. However, many tribal groups are small splinter groups of larger tribes, especially those tribes that were removed from their original land or the remnants of tribes that have almost vanished. They still exist as Native people, often without recognition from state or federal governments, many times having to fight for their right to exist as American Indians.

The term "wards of the government" is archaic; American Indians have been citizens of the United States since 1924 (U.S. Congress), are citizens of the state where they live, and are citizens of their tribe. Many state agencies still use the "wards of the government" phrase, either to absolve themselves of responsibility for American Indians or because they don't know any better. Most agencies consider themselves the "payer of last resort," meaning that every means of funding a service for individuals must be researched and exhausted until that agency has no choice but to fund it from their coffers. For American Indians, this means that the Bureau of Indian Affairs, Indian Health Services, tribal governments, and other such possible source of funds are researched and contacted—a process that often takes months—while a non-Indian would not have so lengthy a wait.

Unfortunately, the general population's attitude towards American Indians today has not changed greatly in 500 years. Because of religious overtones in the colonization of the Americas, the indigenous people already here were viewed as inferior beings in great need of civilization and religious training. Too frequently, service providers today feel that the Indians must be cleansed of their Indian heathenism, must be molded in the likeness of the white society, and that the metamorphosis from Indian to Euro-American must be accomplished before their programs can be of any assistance. The concept appears to be that if an Indian looks, dresses, and acts like a non-Indian he will no longer be a savage but will become homogenized into mainstream American. Sadly, some service providers see this as a necessary preservice step. For example, an Indian man, dignified and proud of his long braids, was told that vocational rehabilitation services for him would not begin until he cut his hair. The reasoning was that the counselor was not likely to get an employer to hire an Indian man with braids, and since the goal for vocational rehabilitation was employment for the client, the client had to be employable. An American Indian man with braids was not considered "employable" by the counselor, so, therefore, the Indian was required to cut his hair (which he refused to do). In this case the Indian was caught between two cultures, and the counselor was caught between the humanistic desire to help and the need to keep his job, which meant to perform well in his position (i.e., obtain successful VR closures).

The arena of American Indian VR is one of complexities and contradictions for both the Indian client and the non-Indian counselor. Many of the obstacles to appropriate services can be removed when knowledge is provided and understanding takes place.

A Native American Outreach Program

A number of articles exist in the literature that explain the how's and

Unfortunately, the general population's attitude towards American Indians today has not changed greatly in 500 years.

why's of dealing with American Indians. This section will focus on how one state actually reached out to increase its services to the Indian people. That state was Florida, where the American Indian population in 1980 was 19,316 and by 1990 had reached 36,335 (Lang, 1992). The Seminole tribe in south Florida has federal recognition, but most of the Indian population in the state are urban dwellers. After some preliminary pro-Indian work had been done that proved the Indian population was in need of VR services, the state began to look closer at its Native people.

The authors of this article met in 1988 at an American Indian Employment and Training Conference, where one (Jerry Lang, who at that time was on the staff of the Florida State Department of Vocational Rehabilitation) was an attendee and the other (Carol Locust) spoke about American Indians and rehabilitation issues at a workshop on American Indians with disabilities for the Native American Research and Training Center, University of Arizona, Tucson.

Among the many topics at this conference was a new national organization of American Indians with disabilities—the WOUNDED EAGLES—a name they had given themselves. Mr. Lang's concern was for the urban and rural Indians who were tribal people but had no locally recognized land-base or reservation. Many of the WOUNDED EAGLES in Florida were from tribes other than those in the southeast, such as Sioux, Crow, or Ojibwe. Many of them spoke English as a second language, and nearly all of

them were reluctant to seek help from government agencies. Some were members of remnant bands, descendants of refugees from the removal process that had very little of their culture left, no land, and no recognition of their tribal roots. These people clearly were in great need of rehabilitation services, yet very little had been done to reach them.

The authors worked out the design of a Florida outreach program for VR focused on tribal people. The immediate need was to educate state VR counselors about their American Indian population. This was imperative because it would be counterproductive to reach out to the Indian population without first training the counselors how to work effectively with them. The Native American Rehabilitation Outreach Program was implemented in March 1989 with designated counselors who had been in the cross-cultural training targeted as the "Indian outreach person" in each of the state's eight VR districts. Also, in response to counselors' requests, an Indian liaison person was hired to assist the counselor in identifying Indian people who needed VR assistance. This person became the first Native American Technician, which will be discussed later.

The first training session included American Indians from the area as well as VR counselors. It also included facts and figures about the Native population in Florida, such as how many Indians, of which tribes, and where they were located. Some of the counselors had never heard a tribal language spoken, so a session on linguistics was included. The cultural aspects of beliefs was another topic of discussion, and a general outline of how counselors might proceed in working with persons from another culture.

From the opening ceremony, it was apparent that this was not going to be a usual state VR workshop. At times there were more Indians than VR people in the workshop, and often the issues under discussion had no (apparent) relationship to vocational rehabilitation. Unsuspecting non-Indians were often caught up in a storm of words, not sure who was speaking to whom, or about what, often feeling the uneasiness and

frustration of tribal members, knowing that VR had been forgotten but having no clue as to why. However, it was clear that the VR issues were related to culture and that Indian identity was the key to the discussions. One of the WOUNDED EAGLES put it this way:

"A few workshops cannot erase 500 years of history between the Native population of this continent and emigrating Europeans."

What, the VR counselors needed to know, has 500 years of history got to do with vocational rehabilitation? The answer was "nothing" if one views VR services as an agency activity and not a counselor-client activity. But if VR is a helping agency intricately intertwined with the lives, homes, and communities of the clients it serves, then 500 years of history has a great deal to do with vocational rehabilitation.

The VR counselors, frustrated because they seemed to be faced with the same yawning chasm of not understanding that they had been struggling with for years, asked questions. There was still a barrier to VR services for Indian people with disabilities, a barrier that neither group wanted. The counselors were asking for answers, and the WOUNDED EAGLES began to talk.

The following table are statements composed from comments of Workshop participants. The statements have been arranged for clarity and brevity of this report.

Outcomes of the Native American Outreach Program

What was the outcome of that meeting and others like it? First, an increased awareness of Indian people on the part of VR counselors. Second, new knowledge for tribal members who did not know what VR was about. Third, the Native American Technician (NAT) Program was begun; and fourth, a dramatic increase in the number of American Indians on VR caseloads. "Vocational Rehabilitation has improved greatly," the counselors reported a year later. "We have more personnel, our services have been expanded, more categories have been included so we can serve more

people. We have started the NAT Program in some areas. We think this is a good beginning."

The WOUNDED EAGLES responded that, as a whole, Florida's vocational rehabilitation counselors were sensitive, caring, and hard working people. The vocational rehabilitation services offered by the state were generally adequate. There now exists a loosely-knit form of partnership between some of the state's VR districts and Indian people in those districts. That partnership could be strengthened to benefit both tribal people and the VR counselors.

From the discussions, discourse, and some disagreements during the workshops we conducted in Florida in 1990-94, four major statements emerged:

- Most Indian people are reluctant to trust non-Indians.
- The majority of Florida's VR counselors were non-Indians.
- Indians are far more likely to trust another Indian than a non-Indian.
- The logical solution, if VR services to Indians were to be expanded, was to have a tribal member act as a liaison between tribal members and the state VR counselors. That liaison position became the Native American Technician, or NAT, that Mr. Watkins wrote about in February 1995:

"In March 1989, the Native American Rehabilitation Program was implemented in the Division of Vocational Rehabilitation. The purpose of this program was to provide outreach services that targeted disabled Native Americans in need of vocational rehabilitation services."

There now exists a loosely-knit form of partnership between some of the state VR districts and Indian people in those districts.

VR Counselors:

We work with disabled people first. Their ethnic origin is secondary.

If we had to learn about every ethnic group we work with, we would not have time to do what we are hired to do: VR work.

We might lose sight of the fact that we work with disabilities, not Indians. VR is not there to address cultural issues.

You can't expect counselors to get into culture that much. We serve too many people; there is not enough time to learn about cultures.

We see a lot of clients that are not motivated to work. Indians don't appear to be motivated, often don't keep appointments, don't show any signs they even want to be rehabilitated.

Is there a lot of difference between Indians who come from reservations and those in urban areas?

Do Indian veterans feel comfortable talking with VR counselors who are not Indian but who are veterans?

Sometimes some of your traditions may conflict with what we need to do as VR counselors. Then what do we do?

Indian Clients:

We are Indian first. That we have a disability is secondary.

How can we get more time for the counselors to learn about diverse cultures so they can be more effective in their VR work?

I am not a client because I am Indian. I am a client because I have a disability. But I was Indian before I was disabled.

We are not asking you to become experts on Indian culture. We are asking to be treated with dignity and respect by becoming aware of our traditions and customs. Learning about our cultures will help you and me to communicate better.

Some Indian people may not want to be rehabilitated, but, as a people, we don't show our emotions often. Motivation is in the heart, and different cultures have different ways of behavioral expression. Also, transportation to keep appointments is a critical problem. Many of our people don't have cars or access to transportation.

Indians from reservations who are new to urban life need a lot more support. They usually seek out local Indian centers. Sometimes they need someone to show them the ropes of living in the city.

(After much discussion). Yes, often a veteran feels comfortable talking with another veteran even if that veteran is white. There is a special bond and honor among warriors that crosses racial barriers.

Ask your Indian client. Each tribe has its own traditions, so the client would be the one to answer that question.

Ironically, in the year prior to program implementation only one Native American client received services statewide. Effective December 31, 1994, some 260 Native American clients were served. Of this number, 204 were served in districts that utilized Native American Technicians.

The Native American Technician Program

The fact that Indian clients respond better to an Indian counselor is no se-

cret. This point was validated by a preliminary program using a prototype of the NAT position initiated in 1988. The program contract was with the Holmes Valley Band of Muscogee Creeks; the first coordinator was Peggy Venagle, assisted by Charlotte Kirkland. While the program was short-lived, the overwhelming response indicated the intense need for programs of this nature. For that reason, the Florida State Vocational Rehabilitation Agency established a pilot NAT Program in 1990. The NAT is an Indian person from the

community and area he/she will serve, who is responsible for outreach to the Indian people in that area and hired with VR funds but through a local Indian organization. Because the NAT has ties to the communities, doors are opened that might otherwise be closed. Having an adjunct counselor who is part of the Indian community has greatly increased Indian referrals.

The counselors insist that NAT's need to be well trained in VR counseling. Once hired, the NAT is assigned to a particular counselor who assists his/

VR Counselors:

We have to try to get you a job, and jobs are available in the WASP community. I know you feel that every step you take into the white world means you are giving up something of your Indian world, but what else can we do for you?

Are you referring to the community liaison person? An Indian person from an Indian community who works with the VR counselors? As you know, we hired an Indian person who served as a community liaison person in one of the districts.

Do you think that having a liaison person will solve all VR problems in working with Indian people?

Time is limited in working with any client. Caseloads increase yearly; they don't decrease. When we took time to come to this workshop, we took time away from our clients. This is some of the most important information I have had in years because of what we have learned here. But it doesn't give me more time or decrease my workload. In fact, it only increases it. How will we get all the paperwork done?

We want to help Indians in VR; we have always wanted to do a good job in our work. The injustices of the past do not have to continue into tomorrow. We are encouraged that we have state administrators that care and that American Indians have met with us.

Indian Clients:

We have a question for you: Is the goal of VR to find people employment? Is it to get everyone into the WASP job market?

Give us someone to work with us who knows about Indians, like another Indian. I know I have to sacrifice something to get a job. I am willing to compromise, but let me choose where I will compromise. Another Indian would understand. Then we can work out all the details.

That is who we mean, a community liaison person who knows who we are and how we feel. You need to hire more of them to serve us in other districts. They need to be there as mediators for us and helpers for you.

Not all, but most problems. The VR counselors need to learn more about our culture and our traditions. You need to have fewer cases so you can do a good job with the cases you carry. The liaisons can help make your workload lighter, easier.

If the state is more interested in the numbers of closures you can get rather than the quality of service to clients, then there is a real problem at the state level. What you have learned here—respect, honor, and dignity—will benefit all people, not just Indians. But it is of no value if you have no chance to use it.

A liaison person between the VR system and Indian people would help us learn how to approach the VR road. And until we can start having cultural sensitivity taught to VR counselors at the college level, we must have workshops such as this one. We as Indian people need to learn how to cope with our frustration, fear, and anger toward the WASP world.

There are some fine VR leaders here today. We are honored to have met with them. We honor you counselors for your hard work. We honor those who are starting a new day in VR for their Indian people.

her NAT to gain the knowledge and experience necessary to represent VR adequately among Indian people. "A preservice training of approximately 2 weeks includes reading VR manuals, becoming familiar with VR words and meanings, going over intake forms, and getting acquainted with all VR counselors in the district," explained one NAT at the workshop. "These activities assure that the NAT has a good understanding of the things that VR can

and cannot do. The NAT then goes out into the Indian community to find out if there are any individuals who need services but have not been identified by the VR system. The NAT becomes the link between that WOUNDED EAGLE and the VR counselor; he/she is encouraged to enroll in classes leading to qualification as a state VR counselor. NAT's must have support of all the counselors, not just the one he/she is assigned to. A NAT's assigned counselor is a partner,

not a boss; and the NAT, the counselor, and the WOUNDED EAGLE work together to establish client goals."

NAT's hold a unique position between the state VR and tribal groups. A NAT was hired in a contract between the State of Florida, Department of Labor and Employment Security, Division of Vocational Rehabilitation, and an Indian tribe, organization, or incorporation. Details of the contract were spelled out in a legal document and the

NAT position description was developed. This was truly a field-initiated pilot program; we (the authors) had to feel our way around many of the technical obstacles, and much of the wording both in the contract and the position description has undergone evolution. For example, some of the contracts now include the opportunity for NAT's to acquire additional training and education toward becoming a VR counselor.

Most NAT's make themselves known at local Pow-Wow's, ceremonies, celebrations, and family gatherings, passing around informational brochures and cards.

The NAT contracts, along with the usual state assurances, contain attachments that identify what is being contracted for, such as "The such-and-such Indians of Florida enters into this contract with the Division of Vocational Rehabilitation to provide the following services to Native American clients of the agency: outreach and referral, case management, and followup services." Under that are listed the explicit duties and details of the agreement. In this manner, the NAT is technically hired by the Indian community, to serve the Indian population, while his/her salary is being provided by Florida VR. This arrangement was developed because of the hiring requirements the state places on the personnel directly in its hire. The NAT becomes responsible both to the state VR and the tribal entity through which the hiring took place.

The contract aspect of the NAT program provides for persons from a culture—who have knowledge and understanding of the culture which VR counselors lack—to provide that knowledge and understanding as an extension of the VR counselor's program. Some

NAT's often go and are readily received in rural/remote areas of Florida's woods, forests, and swamps/glades. Other NAT's work in communities or urban Indian settings, making contacts with persons who otherwise would go unnoticed and unserved. Most NAT's make themselves known at local Pow-Wow's, ceremonies, celebrations, and family gatherings, passing around informational brochures and cards. Many of the people they talk to want to know what VR is. When they find out, many of them can offer several names of people who might need help. And they are not reluctant to do so, because the NAT is one of them.

Although the NAT Program has been very effective, there are few NAT's and thousands of Indians. In VR districts without NAT's, VR counselors and Indian clients must work together to establish appropriate services. The years of meetings have revealed that many counselors, especially new ones, are still hesitant to work with Indian clients and to go into Indian communities. The reason appeared to be the same as before: a lack of cultural knowledge (i.e., they did not feel they knew how to interact with Indians). To remove that barrier, ongoing special training was provided for individual VR counselors who then become "liaison counselors," thus committing themselves to take on extra duty, extra learning (such as what is written in the introduction), and the challenge of cross-cultural VR counseling in order to fill the gap where no NAT was employed in the district. Although having NAT's in place in all VR districts in the state is desirable, it is also important to understand that VR funding levels are a factor in hiring more NAT's and that the NAT Program is still in its pilot phase. Therefore, alternate approaches such as liaison counselors must be used to reach WOUNDED EAGLES until more NAT's are available.

There is one person who has the unique title of being the first NAT to be hired in Florida. This distinction goes to Dawn Mims Praytor, whose connection with her tribe and persons from other tribes in the area and their willingness to talk to another Indian person has cre-

ated an impressive number of new Indian VR clients that is still growing.

Another person, Vicki Welch, has developed her own Indian VR outreach program and is rapidly filling the gaps in services to Native people.


Expansion of the NAT Program

The NAT Program is still expanding in Florida. We are working with other states in setting up their own NAT Programs. However, we ran into other problems when we started to expand the NAT concept into other states. The first handbook on NAT's was developed specifically for Florida and, consequently, we found that some of the technical aspects of contracting were not compatible with the contractual needs of other states and tribes. We are currently attempting to produce a training manual illustrating examples of several different states' contracts or *Memorandums of Agreement* that can serve as guidelines for all states where NAT's might be needed. One such state is Oregon, which recently hired its first NAT using a different form of contract. In Oregon, the NAT not only works with off-reservation people, but acts as a liaison between state VR and several of the tribes. The NAT Program must be flexible to cover the needs in Alaska as well as in Hawaii, or in Pacific Basin territories that have diverse populations. Contractual agreements we provide as guides for the development of other tribal NAT programs must be just as flexible and must include issues of tribal sovereignty. Most tribes are chartered under the *Indian Reorganization Act (IRA) of 1934*. Some are non-IRA government structures; others report some other governmental status (such as treaty tribes, executive order, traditional forms of government, 280 status, or Alaskan Natives' Congressional Action status).

Summary

Native Americans are unique in that they have distinct cultures that differ from the average VR client. The VR counselor needs to be aware of these cultural differences. Indian caseloads

may be assigned to specially trained non-Indian counselors if no Indian counselor is available, or a state agency may wish to establish a NAT program to provide inclusion of Native people in VR services. The Native American Technician Program is a structured, contractual service of a state VR program whereby tribal people are employed via a subcontract with a tribe or tribal entity to provide outreach to American Indian people with disabilities. Having a person from a particular cultural group work with other individuals of that culture is both programmatically and economically effective.

The NAT program has proven to be as great a benefit to the Indian communities as it is to the VR program. To have the number of clients from one particular culture jump from 1 to 260 in 4 years is rather miraculous. To say that the majority of the increase (204) came from districts that utilized NAT's indicates that the NAT Program is a viable method of community outreach to a diverse population. 

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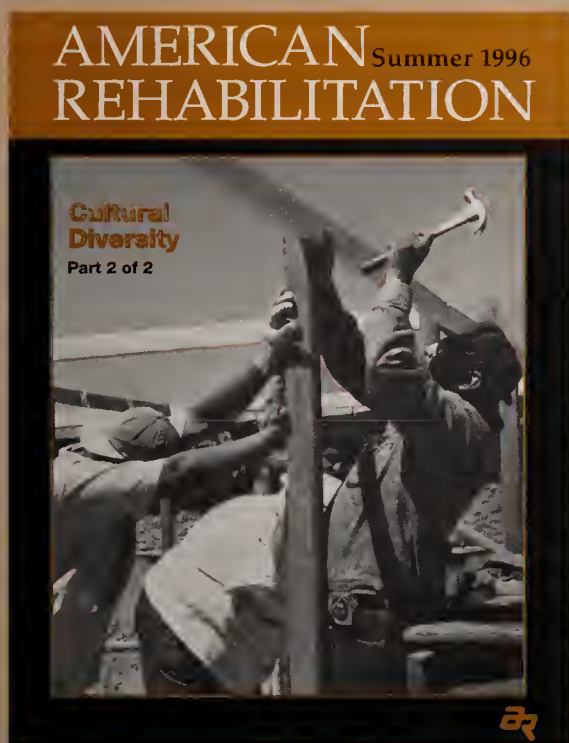
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After Substance Abuse Treatment, Then What?

The NARTC/Oregon Tribal and Vocational Rehabilitation Project

Jeanette Hassin, Ph.D.

Few people today can claim they don't know someone who has or is currently misusing a chemical substance, be it in the form of drugs or alcohol. Even those who are "in recovery," particularly Native Americans, daily confront barriers to successful rehabilitation from substance abuse. Trying to address these cultural, social, and personal barriers that exist for Native Americans, particularly in obtaining vocational rehabilitation services (VR), is a real and significant problem, one that is strongly substantiated by Rehabilitation Services Administration (RSA) statistics. For example, in fiscal year 1993–94 the Salem and Portland, Oregon, state vocational rehabilitation (SVR) branch offices reported that only 3 of 12 Native American clients with alcohol abuse listed as a primary disability achieved successful closures ("26's") (Oregon RSA/VR Branch Offices, 1996, personal communication).

The impetus for the NARTC/Oregon Tribal and Vocational Rehabilitation Project ("Oregon Project") was a request from a member of the Native American substance abuse treatment community in Salem, Oregon, whose chief concern was that people recovering from alcohol dependency could not secure adequate employment, a situation that she saw as directly impacting their self-esteem and sobriety. Upon conferring with the state's regional vocational rehabilitation office, NARTC staff found that the Salem RSA/VR staff agreed with her assessment of the situation. The Salem

RSA/VR staff acknowledged its difficulty in seeing Indian clients through to successful rehabilitation. Subsequent to these discussions, the Native American Research and Training Center (NARTC) submitted a grant and received funding from the National Institute on Disability and Rehabilitation Research (NIDRR) to develop a multidimensional aftercare program for Native Americans in the Salem and Portland, Oregon, greater metropolitan areas who had recently been through treatment for substance abuse. The purpose of the project was to offer participants an aftercare program critical to the stabilization of their recovery and to their acceptance into successful employment through the VR system.

The multidimensional project that developed as a result of these discussions linked Native American treatment programs with VR branch offices. The key element linking the treatment programs and the VR system was an intensive self-empowerment aftercare program sponsored by NARTC.

Presented as an auxiliary component to aftercare, the self-empowerment program provides the recovering substance abuser with a process for increasing his/her sense of self, sense of community, and employability. This is accomplished by learning how to release a way of thinking that is self-destructive to the person and that leads to negative emotions and feelings (e.g., low self-esteem, hopelessness, helplessness). The program also offers a workshop that helps individuals who may be disenfranchised from their culture to explore the unique strengths of their Na-

tive American heritage and by doing so to develop another bridge for succeeding in the dominant society.

As is true for most programs, the coordination of the program turned out to be far easier to put on paper than to put into practice. The NARTC staff found that it was breaking new ground because it was coordinating agencies that not only had never worked together but also in some cases had no idea of one another's existence. The staff also discovered that the commitment of the agencies at each program site was essential to the success of the program.

Issues to be Addressed

1. Well over a quarter of a million Native Americans live in urban areas; another 450,000 reside in suburban areas and outside reservation areas (*American Indian Digest* 1995). Many social services are tribal-land specific or are for specified tribal groups, a situation that disenfranchises the segment of the Native American population not on tribal lands from needed social services.

2. Alcohol abuse among American Indians and Alaska Natives has produced alcohol related mortality rates far exceeding that of the U.S. general population (10.8 times as great for ages 25–34 and 6.5 times as great for ages 35–44) (*Indian Health Service* 1995). This behavior is part of a pattern of self-destructive actions (violence, accidents) whose source is low self-esteem, a sense of hopelessness/helplessness, and post traumatic stress syndrome occurring as a result of the 500 years of interaction between Anglos and Native Americans.

3. Rates of recidivism among people treated for substance abuse run as high as 86 percent 2 years post-treatment, with the majority of relapses occurring within the first 6 months (Marlatt and Gordon 1985). For Native Americans, the high rates of recidivism are the outcome of a number of factors, including socio-economic issues, limited aftercare support, and an inability to see an alternative option to a lifestyle that supported their habitual behavior. These factors profoundly affect the person's ability to access and successfully complete the VR process.

4. The VR counselors are not adequately prepared to deal with the consequences of this historical process or with the cultural values of their Indian clients, whose views are often in conflict with those of the dominant society (of which most VR counselors are members). There is also the tendency by some VR counselors to judge people with a substance abuse disability as irresponsible and to view disabilities such as alcoholism as not quite as "real" as physical problems that are overtly evident. To address this problem, VR counselors must receive training about Native American cultural values and how these values impact the client-counselor relationship.

Setting the Pattern of Links

The agencies that collaborated to make this program possible included the North Portland and Salem RSA/VR offices, the Native American Rehabilitation Association (NARA) in Portland, the administrative offices of Red Willow in Salem, Oregon, and NARTC.

Links and ties among these agencies were the key to the continuing participation, good will, and knowledge transfer that took place in the program. Staff from each agency was able to clarify their agency processes and functions and help contribute solutions to difficult problems. In this respect, NARTC benefited along with the participating treatment and VR programs in learning about the capability and flexibility of each of the participating agencies. The function of these ties cannot be mini-

mized because participant success in the program was dependent on agency cooperation and interaction. As one member of the VR team noted, if this project had accomplished nothing else, it was a success because it raised the awareness of the different organizations to each other's presence, needs, and functions, and by so doing provided a conduit for open communication between Native American treatment programs and the State of Oregon VR.

To enable VR counselors to work more effectively with their Native American clients, NARTC provided Portland and Salem counselors training and assistance through the auspices of two of its other NIDRR funded programs. One program provided cultural sensitivity training to the counselors, giving them background essential to understanding and appreciating the behavior and actions of their Native American clients. The second program helped facilitate communication between the counselors and their Native American clients by assisting VR in implementing a Native American Technician (NAT) position in the office. A very able person was hired as a NAT and soon began acting as a liaison between the counselors in the Salem and Portland offices and their Native American clients. The NAT provided additional support to the clients as they progressed through the VR system. These kinds of auxiliary linkages helped develop a healthy and supportive groundwork on which to set the Oregon Project.

Links and ties among these agencies were the key to the continuing participation, good will, and knowledge transfer that took place in the program.

First, Some Numbers

According to the 1990 National Census, there are approximately 1.9 million Native Americans in the United States (a number many believe to be underreported). RSA reports that American Indians have a 1.2 times greater incidence of disabilities in their population than those in the general population (RSA 1992). Translated into real numbers, this means that 10 percent, or approximately 190,000 Native Americans, have a major work disability. In Oregon, American Indians comprise 1.4 percent (38,500) of the state population, but only 2.1 percent of the American Indian population between the ages of 16 and 64 has been recorded by the Oregon VR as having a work related disability, a percentage that could be low because of a possible lack of access to VR services by Indian people. A substantial portion of this group has substance abuse as a primary or secondary disability (RSA, 1992).

As of fiscal year 1994-95, American Indians represented 2.1 percent of those currently in Oregon's SVR. Their success rate (successfully employed for 2 months following completion training, a "26" closure) is 42.3 percent, the lowest of all ethnic groups surveyed (white, African American, American Indian, Hispanic, and "other"). American Indians enrolled in VR in Oregon with a substance abuse related disability (primary or secondary) prior to the Oregon Project (fiscal year 1993-94) show a rehabilitation rate of 25 percent (3 of 12 individuals), a rate similar to that for the general population for that year, which was 28 percent, or 70 out of 249 individuals (Oregon SVR, 1996). During fiscal year 1993-94, the Salem branch office had no successful closures for Native Americans served by VR. Because alcoholism was considered a critical barrier to successful closure for Indian

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clients, the Salem and Portland RSA/VR branches joined NARTC in this program, providing cooperation and support for this new and innovative multi-agency intervention.

The Participants

Participants for the aftercare intervention were chosen by qualified treatment counselors using three major criteria to determine acceptance into the program: counselor assessment; personal internal cultural strength; and a desire for vocational rehabilitation. While a history of attendance in multiple substance abuse programs did not affect whether or not a person was eligible for this program, eligibility was contingent on whether or not the individual met all the qualifications for acceptance into VR. Most of the participants had been treated for their chemical dependency in a Native American substance abuse program. For the intervention program to have its greatest impact, the NARTC staff decided that it should occur no later than 2 years subsequent to completion of primary treatment for substance abuse. The staff felt that having the intervention and particularly the “Self-Empowerment” (S-E) and “Walking in Two Worlds” training as part of an aftercare program would maximize the benefits the participants received from their treatment programs.

Of the original 29 people who began the program, 22 (9 women, 13 men) completed the self-empowerment workshop training, 8 from the Portland area (4 women and 4 men) and 14 (5 women and 9 men) from the Salem area (including Grand Ronde). The average age of the participants was 35, with the Portland group being on average approximately 4 years older than the Salem group. Half of the Portland participants and 29 percent of the Salem participants had not finished high school or received a GED at the time they began the program. Both groups showed a high rate of substance abuse in their immediate families. Most rated themselves as having a low to fair involvement in Indian culture, with the Portland participants

rating themselves higher on this scale than the Salem participants. Of the original number, seven did not pursue any involvement with VR; one of the seven already had a full-time job and was pursuing an associate degree to become an alcohol and drug counselor.

Each phase of the program focuses on the person's self-regard and life options.

Purpose and Goals

Major barriers to American Indians with an alcohol-related disability achieving successful VR closure are: (1) maintenance of sobriety; (2) ability of the VR counselor to work with someone with that disability (which historically has a low VR success rate); and (3) lack of communication between the Native American client and the Anglo counselor because of cultural and social differences. It is widely accepted that substance abuse among Indians is a symptom of underlying problems, including post-traumatic psycho-socio-cultural stress, and learned dependency (May 1977; Mail, 1980; Jones-Saumty et al., 1983). This project had three specific goals: regain stability, change feelings and perceptions of self-worth that inhibit personal growth, and achieve successful outcomes through the VR system. To accomplish these goals, Drs. Paul Skinner and Carol Locust developed a four-step intervention program, with each phase responding to a different aspect of the participant's education and preparation. Each phase of the program focuses on the person's self-regard and life options. To address issues regarding the alcohol work-related disability (which in some cases is part of a dual diagnosis), VR and treat-

ment administrators worked directly with NARTC staff in the planning and execution of the project. To ensure that problems involving communication between program participants and VR counselors were minimized, NARTC staff trained and incorporated the VR counselors into several aspects of the intervention effort.

Incorporating the Intervention into an Aftercare Program

While treatment has been shown to be very beneficial to people in the short run, many begin using alcohol and/or drugs again within 2 years of finishing their programs. Much of this recidivism can be attributed to the unchanged conditions (e.g., unemployment, lack of skills, low self-perception) of the person's daily life following treatment. The following discussion details the multiple, intertwined components of the intervention and the incorporation of basic aftercare methods and goals into this process and how they are a response to some of the causes of recidivism.

Phase I. The first phase of the intervention was an intensive 4-day workshop consisting of two components: (1) “Bridging the Gap,” and (2) the “Self-Empowerment Process.” Workshops were conducted for groups in both Portland and Salem. As the S-E training is based on a cumulative learning model in which each unit is dependent on the learning and mastering of the previous one, all participants were expected to attend all sessions. If a participant missed a day, the person became ineligible to complete the program. Completion of the program did not affect the individual's VR eligibility.

“Bridging the Gap” was designed to be presented in a 1-day workshop. The workshop, designed by Carol Locust, engages participants in a directed self-discovery of Native American beliefs and practices, health issues, and cultural commonalities and differences, providing them with ancient, historical, contemporary, and future perspectives for understanding themselves as American Indians. This is a very interactive, hands-on workshop that encourages

people to explore their respective cultural heritage and strengths. The purpose of the workshop is to show them how those strengths can be used to live not only beneficially within their own Indian cultures but also to function successfully in non-Indian cultures.

"Self-Empowerment (S-E) Training Program" is a 3-day workshop. Developed by Paul Skinner, the S-E training is based on a theory and intervention that recognize cognitive, motivational, and behavioral processes as the underlying causes of both our problems and our solutions. Directed at a self-analysis of the purposes we assign to our actions and our behaviors, S-E addresses psychological, social, and cultural issues and how as humans we view and experience our lives, health, and the choices we make. The program presents an alternative way of thinking and acting that enables participants to release or unlearn the unhealthy ways in which they had been thinking. In so doing, their sense of powerlessness is released as they start to become aware of their past dependency for happiness on all things outside of themselves. In particular, the S-E process looks at conditioned thinking and how it is manifested in a variety of actions that range from violence to a need to please and through a spectrum of feelings that include fear, anger, guilt, and stress.

Nine separate units (three units per day) were presented in these workshops, covering topics such as conflict, guilt, and stress; coping strategies; critical thinking and decision making; compulsive, abusive, and addictive behaviors; and relationships and dependency.

As with the "Bridging the Gap" workshop, the S-E sessions are interactive in nature. Participants are encouraged to explore both with others and within themselves how they experience the multiple aspects of conditioned thinking and behavior and how they could choose an alternative way that relies on peace within themselves rather than conflict.

Phase II. "Mutual Support Groups" were designed to provide continued support for the individuals in the group as they dealt with everyday life issues,

their sobriety, and working their way through the VR process. Meetings were 90-minute sessions held once a week for 9 consecutive weeks. Sessions took place at locations accessible to the participants. Each of the nine sessions was developed to reflect the nine separate units of the S-E process. Participants reviewed the principles of the process and discussed how they were able or not able to use them in situations that arose during the previous week. In essence, the support groups familiarized them with the tool (for the process itself really is a tool for thinking about choices) as they supported each other during this critical time in their lives. The sessions were particularly beneficial because people were able to ask questions they had about the material and to re-examine and learn from their experiences of current events and situations. Specifically, participants were able to use the process to help themselves through a variety of challenging life situations, i.e., child custody problems, viable employment, maintaining sobriety, and releasing anger. All meetings were facilitated by a person trained in the S-E process.

Participants are encouraged to explore both with others and within themselves how they experience the multiple aspects of conditioned thinking and behavior. . . .

Phase III. "The VR Process" was introduced at different points in the project. The first intervention occurred prior to the Self-Empowerment Workshop. Regrettably, because we did not anticipate the immediate interest in information about VR, the Portland participants did not have a VR counselor

present at their first meeting. In lieu of that interaction, participants submitted a list of questions for the Portland VR staff to address. This situation alerted and prepared us for a similar interest among participants of the Salem group. A VR counselor attended the first meeting of the Salem group and answered a wide variety of questions. She was there for approximately 1 hour. At the conclusion of the workshop, all participants in the Salem group met with and were given appointments with VR Counselors.

Having a VR counselor present at each session of the mutual support group meetings to address any VR-related questions was another important intermeshing of VR with the S-E process. Unfortunately, because of personnel changes within the Portland VR office, this component was not implemented there. It did, however, successfully occur with the Salem group. During and subsequent to these interventions, participants continued as regular clients with their respective VR counselors.

Counselors were chosen to participate in this project by expressed interest, experience, and expertise. Ultimate assignment rested with their SVR branch managers. As their involvement required additional work on their part (i.e., progress reports to the project evaluator, meetings, and training), their wholehearted commitment to the program was critical. As with any client-counselor relationship, if the situation did not work out, the project participant could request a different VR counselor. Only one person requested such a change.

Phase IV. The "Teaching of Teachers" component is the final stage of the intervention. Individuals interested in becoming teachers of the Self-Empowerment program were given training on how to teach the "Bridging the Gap" workshop and how to establish a Self-Empowerment program. This was a challenging phase for all involved as it not only required participants to understand the principles on a personal level but also to be able to convey that knowledge on a broader level to others.

The “Teaching of Teachers” workshops provided the now seasoned participants with a review of the material plus exercises specifically created to assist them in their own workshops. All participants were given the text, *Healing the Self*, and an instructor’s manual from which to work. Following completion of the training, the new teachers were then certified to conduct and to teach the two programs.

Because the ultimate aim of the project is autonomy and ownership of the program by the participants and by the tribes, the program was also offered to representatives from the participating tribal agencies who wanted to incorporate these processes into their own aftercare programs. The tribes expressed a very strong interest in the project and a willingness to assume responsibility for teaching the entire program.

Taken in a larger perspective, this phase of the program addresses more than the above stated objectives. It also embraces the visionary goal of expanding and broadly applying the S-E program wherever there is an expressed desire to have it. This could be realized through tribal ownership of the “Bridging the Gap” and S-E processes and their incorporation into aftercare substance abuse treatment programs. It could also be seen in the growth and expansion of the program beyond these geographic areas. Furthermore, the S-E program could also be applied in other health, social, and educational areas (e.g., as a training component in a child welfare program).

Although this project and the kinds of communication links that were developed within the individual workshops (among participants) and among the different agencies were noteworthy, there were a number of questions that had to be answered about the results of the program: Was there a noticeable reduction in recidivism? Were the lives of the participants enhanced? Did participants successfully complete the VR process? To find answers to these questions, NARTC staff conducted detailed process and outcome evaluations with the full cooperation and input of the participants, for ultimately those individuals experiencing

the program had the insights and understanding so critical to the success and future development of the project.

All participants were paid for their time. While this may be considered irresponsible by some in the treatment field, NARTC staff in fact felt it to be quite necessary. Participants were asked to set aside 4 complete days to learn and use an alternative way of thinking about their lives, problems, and personal situations, and to reflect on their behavior. This is not an easy task. During the program, participants were asked to complete questionnaires and evaluations and to be interviewed. It seemed only appropriate to pay people for each intensive day of learning and work. Ultimately, we felt that it showed respect for the individual.

Evaluation Design

All phases of the program were evaluated by quantitative and qualitative measures. These included attendance and participation in the workshops, participant questionnaires, unit evaluations/quizzes, field notes, interviews with participants, reports on S-E followup mutual support group meetings, and monthly VR counselor reports. Seven assessment scales were used: *The Self-Empowerment Scale* (Skinner and Scott, unpublished); *The Marlowe-Crowne Social Desirability Scale* (Gestein, Ginter, and Grazian, 1985) to measure the validity of participants’ responses to *The Self-Empowerment Scale*; *The Self-Esteem Culture-Free Inventory* (Rosenberg, 1965); *The Rand Health Survey* (Ware and Sherbourne, 1992); *The Perceived Stress Scale*; *The Emotions Scale* (Veit and Ware, 1983); and *The Leadership Scale* (Skinner, Hassin, and McKnight, unpublished). Data collection procedures were identical for both the Portland and Salem groups.

All the qualitative data were coded and analyzed according to a set of defined constructs. These included self-empowerment, self-esteem, health, abstinence from drugs and alcohol, VR compliance (keeping appointments and developing workable plans for educa-

tion and employment), and successful VR closure (“26” closure).

Results of the Evaluation

Quantitative Analysis: Workshop attendance and participation were high for both groups. To measure the latter, we used a scale of 1–5 (1 = the lowest rate of participation and 5 = the highest rate of participation). The rates for the Portland and Salem groups were 3.65 and 3.68 respectively. The rate for both combined was 3.67.

The assessment scales and the evaluation/quizzes were administered at three separate intervals: time 1: pre-workshop intervention; time 2: post-workshop intervention; and time 3: 2 months postworkshop intervention. Throughout the project, little if any change occurred in response to the assessment scales. The nonsignificant results can in part be attributed to a sample size that was too small for the number of questions asked. Parametric statistics (e.g., ANOVA), although reasonable to use for large samples, can be troublesome when analyzing a relatively small sample size.

The respective means of the mean score of participant performance for all nine unit quizzes were the following (maximum possible score = 4.889, minimum possible score = 0.0; standard deviation [s.d.] will appear in parentheses): Portland = 3.882 (s.d. = .393); Salem = 3.859 (s.d. = .353); both Oregon groups = 3.867 (s.d. = .362). The nine in-

Two of the most pronounced indicators of empowerment were reduction of anger and an increase in feelings of control rather than helplessness in their daily lives.

dividuals to whom we were able to re-administer the quizzes showed no significant change in their retention of the self-empowerment material.

After 18 months post-workshop intervention, only 4 of the 22 participants (18 percent) who completed these sessions began using any drugs or alcohol again. One of these individuals is back in treatment.

Qualitative Analysis Results: Field notes taken at the beginning of the "Self-Empowerment/Bridging the Gap Workshop" helped provide a different perspective from which to examine the reliability of the quantitative findings. Several constructs were identified and coded in the data. Of particular interest for this discussion were self-empowerment and self-esteem. Using a scale from 0 to 10 (0 = no sense of self-empowerment or self-esteem and 10 = a strong sense of self-empowerment or self-esteem), NARTC staff coded the field notes from the first meeting and compared them with a wide spectrum of data sources (field notes of the last meeting, post-workshop interviews, mutual support group reports, 2 months post-workshop interviews, and VR counselor reports). The results are shown in Table 1.

As seen in the above comparison, there is strong evidence of change in both self-empowerment and self-esteem with the former increasing substantially over the time of the workshop. Self-esteem also showed an

Table 1 Comparison Pre- and Post-Workshop Means				
Group	Self-Empowerment		Self-Esteem	
	Pre-Workshop	Post-Workshop	Pre-Workshop	Post-Workshop
Portland	2.857	6.456	2.429	4.425
Salem	2.429	6.857	2.286	6.214

¹ Based on the scale 0-10, with "0" equaling no sense of self-empowerment or self-esteem and "10" equaling a strong sense of empowerment or self-esteem.

increase although less dramatically than for self-empowerment.

Two of the most pronounced indicators of empowerment were reduction of anger and an increase in feelings of control rather than helplessness in their daily lives. In concrete terms, this was seen in the substantial changes that occurred throughout the year: five participants regained custody of their children, and many gained full-time employment (see Table 2). One person is also in the process of finishing her GED. Others are currently involved in long-term training (e.g., cosmetology school, nursing program). Project participants, both through interviews and in discussion with their VR counselors, described how they used the empowerment process in their daily lives, choosing this new way of thinking to respond to such difficult and challeng-

ing situations as homelessness, illness, violence, and bureaucratic red tape. One participant had to work her way through Child Protective Services (CPS) dealing with a person who was confrontational. She related to her counselor how she applied what she had learned in the empowerment program. Her counselor noted:

"She kept herself from reacting to the situation in a negative manner. Although she was unable to achieve instant gratification by reacting out of anger, she put the situation in its proper perspective and maintained her self-control and dignity."

Over the course of several months she worked with CPS to increase her visitation rights, went to parenting classes, and without rancor or losing her temper, worked her way through

Table 2
Participants VR Involvement, "26" Closures, and Employment Status

Group	VR Process (Means) ¹			Employment Status (%) ²	
	Appointments	Plans	"26" Closures	Pre-Intervention	Post-Intervention
Portland	4.667	5.833	25 % (n = 2)	0 %	25 % (n = 2)
Salem	7.462	6.539	57.14% (n = 8)	14.29% (n = 1)	64.29% (n = 9)
Combined	6.579	6.211	45.46% (n = 10)	4.55% (n = 1)	54.55% (n = 11)

¹ Based on a 0 to 10 point scale, 0 = no progress; 10 = consistent and continued progress.

² Based on a total number of 8 for the Portland group and 14 for the Salem group.

many frustrating experiences to regain custody of her daughter.

The impact of the S-E process has also been seen in what is known as the “nudge effect” (i.e., although the desired result does not occur, a positive effect does result because of the intervention effort). This kind of effect occurred for a participant who suffered from chronic depression. Although this person was compelled to quit his job because of his mental state, he did not follow his usual pattern of turning to alcohol when this occurred. He attributes his ability to cope with his depression without alcohol to the tools he acquired through the S-E process. After 1 year, he has once again been able to secure full-time employment. Other behavioral changes of this kind were observed among the participants. A woman with a long history of choosing anger and violence in response to problems became, over the course of the workshop, increasingly better able to express and to resolve personal problems without the volatile reaction traditionally part of this person’s behavioral repertoire. While she did not make it through the VR process, the changes in her actions and words were of such a noticeable quality that they were frequently noted in reports, comments, and interviews by a variety of individuals, including the instructor of the workshop, the program assistants, the evaluator, and, most importantly, the other participants.

A strong sign that the intervention was achieving its desired objectives was seen in the sizable number of project participants who successfully completed the VR process. To date, results show sustained VR involvement for the majority of the participants. They are keeping their appointments with the counselors, developing employment plans, and successfully completing the process. Once again, a 0 to 10 scale was used to code the results for participation in the VR process (see Table 2). As the table shows, very few participants from the Portland group enrolled in VR. Unforeseen personnel changes in the Portland VR office led to logistical problems that affected the participation of

the Portland group in the VR process. This along with the fact that two participants moved out of state and two resumed their substance use (one of whom is currently in treatment) have impacted the number of people who have worked through the process. From the Portland group, two have successfully completed VR and are employed full time, and one is continuing to work through the VR process.

Of the 14 from the Salem group who completed training, 3 are currently receiving VR training and 9 are working full time. Of the nine working full time, one has remained in her present position as she continues her education, and eight have permanent full-time jobs secured as a result of VR. This is an increase of 800 percent for Native Americans successfully completing the VR process out of the Salem office. Information is not available on two participants whose files were unsuccessfully closed.

The third major outcome for the project was the successful training of new teachers of the “Bridging the Gap” and “Self-Empowerment” programs. Three participants chose to do this: two from Portland and one from Salem. They, along with 10 tribal and VR counselors, were trained in February 1996. From that group of new teachers, nine members team-taught three new groups of participants in March 1996. All three original participants were among these teachers.

Discussion

Based on the results of our analysis, there is evidence supporting a strong and positive impact for this intervention. Our findings show that the group of participants that had the strongest developed links between the treatment agency and the VR branch office appeared to have benefited the most from these interagency ties, enabling it to receive important information and support as participants moved back into the workplace. This effort was further supported by the larger positive change in self-esteem among members of this group and their ability to use the VR

resources more successfully than the group that had less involvement with VR personnel. These counselors created a bridge of great strength from their personal efforts to participate in the project, their continued attendance at support group meetings throughout its 9-week cycle, their provision of VR services at a tribal facility, and their subsequent involvement in alcohol and drug prevention program events. Making and keeping these connections, while extremely important, were strongly enhanced by the S-E workshop. Comments from the interviews as well as management of personal and job-related problems and issues clearly indicate that most participants were successfully applying the S-E principles they learned to life situations and in so doing improved their own self-sufficiency.

The results of the first phase of this project suggest that the efficacy of the intervention rests on three nesting components: personal empowerment (the function of the individual’s perseverance and commitment to the intervention), the VR process, and a new sense of personal self-sufficiency.

Modification of Criteria

Certain changes were made in the project based on the appropriateness and functionality of the measures. While we will continue to use quantitative measures to discern change, we recognize that until the data base is large enough, regular parametric statistics cannot be used with any reliability. As we increase the overall number of people participating in the program, this will become less of a problem. However, the number of actual questionnaires has been reduced from seven to three. Those that are being kept reflect the basic components of self-sufficiency: *The Self-Empowerment Scale*, *The Rand Health Survey*, and the self-acceptance scale (*Marlowe-Crowne Social Desirability Scale*). The demographic data collected has also been reduced to decrease redundancy.

A second modification was made in the criteria for participation. We found that it was necessary for participants to

have some assurance of not being homeless after completion of their substance abuse treatment. This level of stability was necessary for them to be able to focus on the S-E process after the workshop and to continue to work with VR. One participant, who had made tremendous progress throughout the workshop and was working with his VR counselor on a regular basis, developed an erratic pattern of contact once he was homeless. Another participant who regained custody of her child and is currently in a training program has had to fight with this problem for most of her training period, moving from the home of one acquaintance to another while attempting to complete her studies.

This intervention project has produced several positive results.

Conclusion


This intervention project has produced several positive results. First, it provided a conduit for networking and developing links between the Indian community and the regional VR branches and among the different projects run out of the office of NARTC. These links have fostered not only the development of new sources of information but also a greater understanding between the community and Oregon State VR. These links have also enabled the new generation of teachers to accept and use these networks as natural sources of information and conduits for their clients. Second, the project appears to have had a strong impact on the stabilization of sobriety. While it often takes more than a year to determine such an effect, the results after a year have been very encouraging and justify the kinds of thinking tools the S-E intervention offers. Third, as with the stabilization of sobriety, the impact the S-E process has

had in relation to the health of the individual can be seen in the "anchoring" of the person, even when his/her ultimate goals are not reached. This effect should not be minimized, as it shows the person choosing to use the empowerment process in situations that he/she would have otherwise found beyond his/her ability to cope with. The fourth, and in many ways the most concrete, result is the number of participants who have worked so successfully in maximizing the potential of VR. Increasing the number of successful closures by 800 percent in one branch office alone is a remarkable result.

Although the actual number of people who have gone through this first phase of the project is not large, the success of the program warrants serious attention as it proceeds through its second phase and the next generation of participants. During the first year of operation, the project involved the cooperation and expertise of five agencies (two Native American treatment programs, two VR branch offices, and NARTC) working together to overcome the logistical difficulties of the project and to make the plan a reality. Today, the program has expanded and incorporates two additional tribal substance abuse treatment programs. In this second phase of the program, the VR counselors are working closely with the treatment counselors to make the S-E aftercare program a successful intervention.

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Embracing Diversity in Rehabilitation in Pacific Cultures



This paper presents a unique and personal view of rehabilitation issues, needs, and expectations of individuals with disabilities in seven diverse Pacific jurisdictions. The vastness of the Pacific and its unique cultures offer a glimpse of island living unlike any other geographic area of the United States. Presented are the authors' views drawn from their experiences and observations in rehabilitation services.

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The Pacific is unique with regard to geographic, familial, political, economic, and social issues that impact both rehabilitation services and individuals with disabilities. The island environments, influenced by political, economic, and social change, are in a constant state of evolution. Island communities are being impacted by change at all levels—at the local level in each unique Pacific area; at the regional level with all island entities competing for the same dollars, programs, and services; and at the national level where changes impacting the future of island entities continue to be discussed, argued, and negotiated.

In the political arena, change has resulted in new nations and government structures. United States Government levels of funding are being reexamined and, in some cases, reduced. Reductions have occurred in the Federated States of Micronesia, the Republic of Marshall Islands, and the Republic of Palau. Economic stability is a goal rather than a reality in a geographic area that has long been dependent upon subsidies from the United States, foreign governments, and private business enterprises. With limited local resources and capacities to develop a sustaining economy, the islands have become more dependent on a "cash economy." The traditional custom of a subsistence economy is a thing of the past for most of the island entities in the Pacific.

Social environments of family and community have affected this process

of change with traditional practices and cultural values being challenged, reexamined, and modified. For example: Hull (1991) noted there is an "increased dependence on imported foods, the expropriation of healthcare by specialists, and more generally, the far-reaching transformation of lifestyle making incalculable changes to both physical and cultural health in the region" (p. 22). Health-indicated challenges throughout the Pacific are dominated by diseases of affluence (the effects of tobacco, alcohol, drug abuse, stress, poor nutrition, and lack of exercise). Oneison (1991) indicated "one major cultural change is the transfer of resources from land and water to cash, a change that breaks up the unity of the clan and enhances individual family independence culminating in changes in one's identity" (p. 5). Finally, Marcus (1991) observed that "the breakdown of the family structure is drastic and people do not know how to cope with the changes taking place. Everyone wants change but we do not know how to deal with the problems that result from changes" (p. 9).

Change in the Pacific is inevitable. As the American historian Charles Beard stated, "History is irreversible. Sovereign or not, no island people can return to their condition at discovery. All of what they are today is because of what they have been through..." (in Grattan, 1981). The impact of environmental (social and communal) change on an individual with a disability in the Pacific is both exhausting and promising. Opportunities for inclusion in all levels of the culture and community are enhanced, although often slow to fruition. Examining established systems and institutions, such as rehabilitation services, medical care, ed-

ucation programs and opportunities, and political and social systems, as well as valuing the local practices that drive these systems, is essential prior to suggesting change. The challenge is for the people anywhere—particularly in the Pacific communities—to be prepared to deal with change firsthand, evaluate its impact on individuals and environments (cultural, social, economic, and political), and determine how to fully integrate change into their day-to-day life.

Understanding Rehabilitation in the Pacific

Any approach to a rehabilitation service, research, and training provision must be developed and implemented within the unique context of the geographic area. To be successful each approach must reflect each island's cultural uniqueness.

To understand and appreciate the diversity of issues impacting individuals with disabilities in the Pacific, one must comprehend the size and uniqueness of the Pacific area, which covers in excess of 5 million square miles of the Pacific Ocean and includes numerous political entities as well as many cultural and social groups.

Each of the seven entities served by the Rehabilitation Research and Training Center of the Pacific (RRTCP) is unique and diverse in geography, culture, and people, as well as in political, economic, social, and kinship systems. To group these entities together is a disservice to indigenous Pacific cultures.

Before we expand on the issues, we need to consider the differences of the State of Hawaii in relationship to the other Pacific islands and communities. Hawaii achieved statehood in 1960, and is truly a state that represents a culturally diverse and complex environment. It has a large urban population in the city of Honolulu as well as many rural communities in the outer islands and the North Shore of Oahu. Hawaii is afforded the same accountability for its resources, services, and future directions as the other 49 states. The availability of rehabilitation related services and resources

are more expansive and sophisticated (although surely not without need for further development and refinement) than the other Pacific entities.

Geographic Issues

The geographic differences and environments that exist among the island entities cannot be overemphasized. The seven island entities—Hawaii, American Samoa, Marshall Islands (RMI), Federated States of Micronesia (FSM), Northern Marianas Islands (CNMI), Guam, and Palau—that comprise RRTCP in the Pacific lie scattered throughout thousands of square miles of the Pacific Ocean. The islands range from a variety of small reef islands to large mountainous, volcanic islands. The Pacific is frequently exposed to natural disasters which alter the quality of life of its residents. Earthquakes, typhoons, drought, power outages, and dependence on imported goods affect daily living.

A common practice in the Pacific is to transport emergency related critical medical care cases to Hawaii or the U.S. mainland for treatment.

Associated difficulties include infrequent or inconsistent air transportation (inter-island as well as mainland connections). For example, American Samoa is served by one air carrier with limited (usually one flight) and inconsistent schedules during any given week, limiting delivery of food items, mail, and air freight. Some islands are not easily accessible by air or by sea, especially in the outlying islands. Availability of essential or emergency med-

ical care and equipment is impeded by insufficient air/land/sea cargo and transport. A common practice in the Pacific is to transport emergency related critical medical care cases to Hawaii or the U.S. mainland for treatment. These cases usually include in-

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dividuals with life threatening disabilities (i.e., spinal cord injuries, head trauma, stroke, heart disease, and renal failure). The infrequency and inconsistency of air service hamper this practice as does the cost of transport service.

Geographic conditions affect the use, maintenance, and assistive devices affordable for individuals with disabilities. Sidewalks in most of the Pacific are clusters of cement, coral, sand, or dirt. Tropical rains often overwhelm local sewer lines and drainage capacities become overextended. Pot holes are commonplace and, in many of the local villages, roads are paved with crushed coral or volcanic rock. The island environment fosters corrosion of metals and the rapid breakdown of plastic or rubber. Most assistive technology devices are made of metal (wheelchairs, canes) and break down in the Pacific within months of purchase and consequently have limited value. There are no local facilities currently available to provide maintenance or repair services for this equipment in Pacific areas beyond Hawaii.

Other environmental factors contributing to the incidence of disability in

the Pacific include poor sanitation, tropical diseases, infections, lack of preventive awareness, limited medical care, lack of or limited communitywide social and rehabilitation services, and cultural stigmas related to disability.

The questions need to be asked, "What can be done locally to improve necessary services and, more importantly, how can these necessary services improve the quality of life for individuals with disabilities?"

Each island entity has a population center or capital where most human services are provided. The outlying islands are infrequently served by health officials and social service providers, including vocational rehabilitation. The availability of services and resources for individuals with disabilities on these outlying islands is virtually nonexistent. Outreach to these islands fosters frustration on the part of the individual with a disability and his/her family because of unfulfilled promises made for medical and rehabilitation services, equipment, and opportunities. Subsistence living on the outer islands is the norm, while in the population centers there is a heavy reliance on imported

goods. The "cash economy" takes precedence in the population centers.

For an individual with a disability, a wheelchair user, or an individual who is homebased, the Pacific climate plays host to increased risks for a number of otherwise preventative health conditions (Seekins et al., 1993). Such secondary conditions are receiving significant attention from the public health sector as part of national disability prevention initiatives (National Council on Disability, 1986; Houk & Thacker, 1989; Pope & Tarlov, 1991). Marge (1988) defined secondary conditions as those conditions that may be experienced by an individual after they have a primary (or first) disability. They may range from such medical complications as pressure sores and urinary tract infections to problems of psycho-social adjustment, such as depression, to environmental issues, such as access problems (Seekins et al., 1991; Graitcer & Maynard, 1991). In this framework, having a disability is viewed as increasing one's risk for a variety of preventable problems that can limit good health, functional capacity, and independence.

The tropical environment plays host to a number of secondary complications resulting in more severe, acute disabilities, such as diabetes, which in turn often results in the amputation of extremities. With changes in the Pacific diet and lifestyle, there has been an increase in stress-related disorders, hypertension, gout, and arthritis. Mental illness and substance abuse cases are on the rise as are complications arising from accidents (i.e., head trauma accidents and injuries) and acts of violence.

To illustrate, a young man from San Diego who was a wheelchair user, was called to his home island because his mother was ill and needed assistance. He returned to the island, built an accessible home, and provided his mother with food, money, and a car. He was receiving social security benefits from California and made yearly trips to sign the necessary forms to continue to receive this benefit as a California resident. (This benefit for individuals with disabilities is not available in the islands outside of Hawaii at this time.)



Exercise class for older persons and persons with disabilities in the Physical Therapy Clinic at the Palau National Hospital.

The tropical environment and the limited rehabilitation and medical services caused difficulties. His wheelchair broke down frequently. He was a heavy man and needed daily personal care and support services. He was proud and did not want to burden his mother or young siblings with his personal care. He had extreme bed sores that worsened. In the heat and tropic climate, he was prone to complications as his immune system did not allow him to perspire. Air conditioning was unaffordable. He suffered constantly from systemic swelling. The available medical services were ineffective in minimizing his infections and other complications. Within 3 years of his return to the island, he died.

Stories of this type might be viewed as one-time, single case scenarios. However, they can, and do occur in all of the Pacific islands. The implications are obvious. Questions need to be raised. Why did this happen? What could and/or should have been done for this individual considering his situation and its numerous complications?

From a Western perspective, the first thought that comes to mind is the need for services available through independent living and the need for empowerment.

Yet larger issues loom: What services did this individual need to sustain himself and his disability? What support services were available for him and his family? What could have been done for him to enable him to sustain his lifestyle on the island? What training was needed or could have been implemented to assist his family and the medical, vocational rehabilitation, or independent living personnel that visited him periodically? What medical information could have been provided to all involved in this young man's life? What policies could have been implemented to ensure he had equal access to affordable equipment, quality and equitable services, and appropriate care? Who should have been advocating for this young man's life? What types of benefits can provide economic assistance?

The island communities are trying to hold onto traditional values and, at the same time, compete and function within a changing society.

These are very real issues impacting individuals with disabilities living in the Pacific.

Ethnic and Social Diversity

The richness of ethnic diversity and social differences are evident throughout the Pacific. This diversity significantly impacts the development, planning, and implementation of rehabilitation service systems throughout the area. Each ethnic community provides a unique opportunity for collecting informative data on culturally relevant rehabilitation beliefs, practices, strategies, and solutions. The island communities are trying to hold onto traditional values and, at the same time, compete and function within a changing society.

The Pacific offers a complex environment for the study and identification of ethnic and social uniqueness, practices, and beliefs with regard to disability. Put in the context of "how to best serve" individuals from unique cultural settings, these differences provide an opportunity to identify or develop culturally appropriate services and strategies that will work with diverse populations. Such diversity provides a challenging environment to address best practices in rehabilitation in the Pacific as well as to explore the transfer of knowledge to mainland ethnic groups facing isolating or cultural conditions (e.g., rural communities, Alaskan natives, and American Indians).

The 1990 census population data for the State of Hawaii, shown in Table 1, provides an indication of the diversity of its strategic location or "gateway" status in and around the Pacific. It is truly a gathering pot of people, cultures, and social practices.

The ethnic populations throughout the Pacific have differing customs, beliefs, and lifestyles that need to be considered in introducing concepts such as consumer involvement, independent living, supported employment, and vocational rehabilitation. Traditional customs differ as the scattered and often isolated islands produce local adaptations and inventions to fit into a mainstream of the host island.

The challenges facing rehabilitation service providers in identifying the underserved and underserved within their island communities have begun to surface, and many are not prepared to address these needs. Consequently, many people from these remote island communities have relocated to Hawaii in search of education, employment, and healthcare. This and the ongoing immigration of individuals from the Pacific Rim (i.e., Japan, Korea, China, the Philippines, and countries of Southeast Asia), each trying to preserve their traditional culture, assure that the diversity of cultures in Hawaii will continue to exist; and diversity issues significantly influence the provision of rehabilitation services.

Communication and Language

Although most individuals in island communities speak English—as a second language—communication throughout the Pacific is difficult because of the variety of languages in each island entity. Vash (1994) stated that "... language is a critical factor in understanding culture. When you try to understand and analyze beliefs, ethical values, and convictions, there are deep concepts that are very much tied to language. When you rely on translators, you lose a great deal. Individuals who can speak two languages are almost essential."

At least nine major languages, with regional dialect variations, can be dis-

Table 1
Hawaii Population by Race & Ethnicity

Race/Ethnicity	1990 Population	Percent of Total
White	369,616	33.4
Black	27,195	2.5
American Indian	5,099	0.5
Asian	522,967	47.2
Chinese	68,804	6.2
Filipino	168,682	15.2
Japanese	247,486	22.3
Asian Indian	1,015	0.1
Korean	24,454	2.2
Cambodian	119	0.0
Vietnamese	5,468	0.5
Hmong	6	0.0
Laotian	1,677	0.2
Thai	1,220	0.1
Other Asian	4,036	0.4
Pacific Islander	162,269	14.6
Polynesian	157,749	14.2
Hawaiian	138,742	12.5
Samoan	15,034	1.4
Tongan	3,088	0.3
Other Polynesian	885	0.1
Micronesian	3,968	0.4
Guamanian	2,120	0.2
Other Micronesian	1,848	0.2
Melanesian	291	0.0
Other Pacific Islander	261	0.0
Other Ethnicities	21,083	1.9
Total Population	1,108,229	100

Source: U.S. Census Bureau, 1990 Census, Summary Tape file 1A.

tinguished within the geographic region of Micronesia alone (Carter, 1984). For individuals with disabilities and their families, the cultural practices and language differences may present problems if services are only provided within a Western context. Issues may arise for service providers in trying to fit a Western rehabilitation practice (i.e., the concept of independent living) into a cultural mindset or framework that is not compatible with local custom. The suggested practice may be beneficial only if it can be modified to fit the cultural context and be fully described in the mother language. For example, the concept of independent living when described by such terms as em-

powerment, advocacy, personal choice, and living independently, goes against Pacific Island cultural practices of respect, being humble (*Fa'a aloalo*—Samoan; *mal muri*—Palauan), family choice and involvement, and living and being with the family. Descriptive words in the English language do not always mean the same in the local language. Words that mainland rehabilitation practitioners use to describe the work they do takes on a very different meaning if not shaped and presented with consideration of the language variances of the Pacific. For example, in most Pacific languages there is no word for "rehabilitation," but rather a cluster of descriptive terms that

define a function or nonfunction of the body or mind to describe the disability. Since the word "disability" describes a wide range of conditions, there is the possibility of misinformation. Cultural and linguistic diversities present unique challenges for the provision of comprehensive rehabilitation services as viewed from mainland and U.S. Governmental perspectives.

Familial, and Kinship Systems

The richness and diversity of the social, familial, and kinship systems throughout the Pacific are the essence of the various cultures. Within these cultures, the concept of the extended family is basic to the nature of its people and has evolved over centuries. Nearly every family owns or has the use of land in its community. A subsistence existence has long been a way of life throughout most of the outlying Pacific. The belief is that there is no need for a welfare system, because everyone has a family and is cared for by that family.

The value placed on the family unit has a strong impact on how individuals with disabilities are treated and viewed by the Pacific family and the community. The principle of interdependence is an important aspect of family and community living. It has been said that the Micronesian attitude toward people with disabilities is humane and wholesome. Sixteen years ago, Sanchez (1979) observed that "... persons with disabilities are basically accepted for what they are and what they can do. They are not looked down upon, or considered a burden to society. They are cared for just like anyone in the culture." This observation remains true today.

As with many ethnic groups on the mainland and worldwide, the family plays an integral part in the life of the family member with a disability. The concept of independent living is different from that demonstrated on the mainland United States. In many of these entities the concept of interdependence among family members and members of the extended family is

more socially desirable than being fully independent.

Western civilization has focused on the individual as the primary unit of experience. Samoan culture has always seen the *aiga potopoto* (extended family) as the most important agent in the human equation. Western philosophy emphasizes the autonomy of the person. The self-esteem, assertiveness to obtain rights or needs, and the individualization necessary to become a unique personality are all questioned values in the Samoan psychological system (Whitney, 1989). Western mental health ideology emphasizes personal functioning such as intelligence and work skills, while the Samoan world view tends to emphasize relationships to family, village, and church. A person has an identity only so far as that person can demonstrate his/her connections to the *aiga*. Personal needs, goals, and eccentricities must be downplayed for the good of the family group (Whitney, 1989).

In Samoa and throughout most of the Pacific, there remain strong inhibitions against airing family problems to outsiders. The status system requires the head of the household and/or the chief (*matai*) to take care of internal problems so the family is not caused any embarrassment in the larger community. *A malu le fale e malu i fafo* (what is sheltered at home, let it be sheltered outside) is a Samoan proverb which reinforces the value in keeping problems within the family. The *matai* represents the family in any formal public gathering and represents the extended family in the village council or chief's council. Individuals do not represent themselves (Whitney, 1989).

Even as these island communities continue to evolve and function in a technologically sophisticated world, three systems are ingrained in their social and cultural makeup:

- the maintenance of land tenure systems that protect the local people and families;
- a strong alliance to church and religion; and
- loyalty to government, village, and family.

The social and kinship relationships are intricate and require consideration when introducing new health-related concepts and rehabilitation services. With increasing emphasis placed on family involvement and natural supports in mainland rehabilitation services, the knowledge gained and practices developed in the Pacific may provide expanded strategies for mainland family support. Research in this area should increase mainland sensitivity to Pacific people and cultures and result in an identification of "best practices" of family involvement in rehabilitation.

Political and Government Perspective

All of the island entities have discrete, unique, political and governmental perspectives. There is a common theme in the Pacific Islander's interest and commitment to maintaining ties to the past, preserving the respective island culture, and maximizing an active and participatory role in self-determination. Through much of the developmental history of each of these islands, there has been a reliance on outside forces to provide expertise and governance.

The Pacific political and governmental systems are in a state of evolution

with each entity in the process of examining or restructuring its current relationship to the United States. Table 2 provides an overview of the political status of each of the seven Pacific entities.

The intricacies and uniqueness of these island governments are described for two entities: American Samoa and the Federated States of Micronesia.

The political and governmental structure in American Samoa combines a traditional mode of operation (i.e., the *Matai* system) with a Western style of governance. The influence of religion and family play a key role in governmental decisions.

Micronesia is composed of four states—Pohnpei, Yap, Chuuk, and Kosrae—each of which has its own state governance. The national government is located in the state of Pohnpei. From a political and governmental standpoint, each state is developing its own organizational and political culture and has established priorities and is operationalizing its constitution. Interrelationships and cooperation between the states and the national government is an ongoing debate.

Anderson (1992), in a recent assessment of the political environment in one of the Pacific freely associated national governments, found a very different en-

Table 2
Political Status of the Pacific Entities

Pacific Areas	Status/Type of Government
American Samoa	Unincorporated U.S. Territory (1900)
Northern Marianas Islands	American Commonwealth (1977)
Federated States of Micronesia	Independent State in Free Association with the United States (Since 1986)
Guam	Unincorporated U.S. Territory (1890)
Hawaii	State of the United States
Republic of Palau	Independent State in Free Association with the United States (since 1994)
Marshall Islands	Independent State in Free Association with the United States (since 1986)

Source: Ryen, 1993.

vironment than that found in Hawaii. U.S. legislation and funding, which once supported rehabilitation and special education services, were no longer applicable. Consumer and advocacy groups in the island entity were not organized and there was little evidence of adults demanding or supporting rehabilitation services; few groups were organized for political action; there was no formal organization of rehabilitation professionals; and there was no evidence of any professional organization attempting to influence political decisions regarding rehabilitation services for individuals with disabilities.

Individuals with disabilities have had limited involvement in programs and services afforded them.

The political and governmental arena in each of the island entities needs to be more fully explored. In the island areas, the government agenda drives the implementation of services and allocation of resources (human and monetary) to sustain these services. In each of the island areas addressed, the political and governmental arena is untapped. Individuals with disabilities have had limited involvement in programs and services afforded them. Island governments may not fully be aware of how decisions made for allotment of resources impact the very essence of life and quality of life for individuals with disabilities. For example, a parent from Palau wrote "... we have established a parent network to work with special education ... we have

little influence in how the system operates ... at the local level ... we have no leverage." A young man in a support group in American Samoa said: "... we really don't have a voice in our community." He then expressed a need for transportation services, wheelchair ramps, and special transportation for people with disabilities (e.g., handivans). A service provider from Micronesia stated "... we are currently negotiating with the U.S. Government to reinstate VR services in our constitution. We have many disabled people but limited funds and no resources ... Most of our services for adults with disabilities are over."

The demand for basic infrastructure and services, such as sewer, water, power, and health services, are critical in these government entities. Burdened with limited resources and infrastructure, and lacking the labor pool necessary for full-scale development, the islands struggle to bring their economies in line with the material wealth of the industrialized West. New roads, inter-island ferries, airports, power plants, and communication networks rank high on the wish lists of the emerging Pacific states (Ryen, 1993).

The political systems in each of the island entities are distinct and delicate and need to be treated as such. Their involvement in the process of rehabilitation needs to be encouraged and solidified.

Employment/Economy Perspectives

Employment figures are affected by the cultural mores and socioeconomic factors of each Pacific entity. The traditional concept of employability of individuals with disabilities is viewed differently in the Pacific Islands. In the State of Hawaii—particularly the Island of Oahu—and in the Territory of Guam, employment opportunities for individuals with disabilities seem to be more readily available than in the remaining island entities. These two developed areas have a more defined economic base than the other Pacific islands.

Government is one of the greatest sources of employment everywhere in the Pacific. The government of Palau employs nearly half of the Republic's total labor force (40 percent work for federal and local governments). One out of six persons in Guam's labor force works for local government. In Micronesia and the Marshall Islands, the government employs up to two-thirds of the available local labor force. Since World War II, government has been the major provider of jobs and incomes in the islands (Eastly, 1994). Throughout the Pacific, government employment is the norm (ASG Economic Development Planning Office 1990 Census Release). In view of these facts, it would be interesting to know what percentage of the government labor force are persons with disabilities.

Most of the Pacific entities rely heavily on U.S. dollars to maintain their economies. In 1991, U.S. aid totaled \$84.8 million to Guam, \$55.5 million to the Northern Marianas, and \$56.6 million to American Samoa. Palau, the Marshalls, and Micronesia get 80 percent of their income from U.S. subsidies (Ryen, 1993).

The tourist industry is a principal economic influence in Hawaii, Northern Marianas Islands, and Guam. Although tourism exists in the other entities, it is less developed. Hawaii, with one of the lowest unemployment rates in the nation, seems to have reached its natural rate of unemployment. The gains in employment can be equated to an increased standard of living. Micronesia, the Marshall Islands, and the Republic of Palau are attempting to develop new and ongoing revenue sources through economic growth based primarily on investments in fisheries, tourism, and agriculture. In these areas, new business revenues have come primarily from fishery development. Tourism has not developed as rapidly as expected and agriculture-based products (pepper and citrus fruits) have reached limited Japanese and U.S. markets (Eastly, 1994). Job opportunities for individuals with disabilities are limited in the entities beyond Hawaii.

There are no common minimum wage laws in the Pacific entities. For instance, the minimum wage on Guam is \$4.25. The government minimum for Palau is \$2.00 per hour. American Samoa's minimum wage ranges from \$2.10 to \$3.35, depending on the type of employment. The Northern Marianas Islands' commonwealth agreement negotiated an exclusion from minimum wage laws (Ryen, 1993). The minimum wage on the Marshall Islands is \$1.50 per hour. There is no established minimum wage in Micronesia. On the mainland and in Hawaii job opportunities at the entry level (i.e., food service work at McDonalds, Pizza Hut) are common practice. However, in the Pacific, these are considered careers and usually are family operated businesses.

Another growing trend impacting the economy and availability of jobs within the islands is the migration of skilled and unskilled workers. Most service jobs (i.e., maids, cooks, hotel jobs) are taken up by an influx of immigrant, unskilled workers from the Philippines and other Pacific Rim nations. Employment opportunities for persons with disabilities are limited or non-existent, especially for individuals with limited English and work skills.

Cultural practices influence economic and employment practices, which in turn impede the availability of employment options for individuals with disabilities, who may not have the ability to do jobs other than those being done by nonlocal workers. There is a stigma attached to a native Pacific Islander doing the menial

work that is now done by immigrants. Galea'i (1994) said, "In the Pacific we address our work from a different perspective. It is not a separate life from our domestic life as it is in the Western culture. Work is integrated into our living environment. As a greeting, Pacific Islanders like the Tongans, say 'Malo Galue,' or 'good work.' At the close of the working day, Samoans frequently say 'e mua mua,' I go first to do other chores." Galea'i (1994) further stated "We mix our work, play, and living as part of our community. We are bound by a fellowship of endeavor often towards the goals of this broad community to which we contribute the best of our abilities, in which each contribution is recognized and credited. In our traditional mores all voices are heard and our individual success

contributes to the success of the common enterprise and to the success of others. We can disagree and often do, holding different viewpoints without withdrawing from the community."

Successful employment outcomes are usually the result of full family support and acceptance of the individual's contributions to the family and community.

Orientation to employment for all individuals must, in most cases, involve the individual's family. Successful employment outcomes are usually the result of full family support and acceptance of the individual's contributions to the family and community. The integration of and reliance on local cultural practices is necessary for successful placement and employment outcomes for individuals with disabilities. The economic climate and limited opportunities for employment impact services for individuals with disabilities, their families, and the community at large.

The Challenge for Rehabilitation

A growing concern throughout the Pacific is that westernization is causing the deterioration of the culture, family, and social systems. There is concern that the homogeneity of the culture within each entity is being lost due to outside influences. Throughout the Pacific Islands, and among its people, there remains a strong adherence to tradi-




Demonstration of special beach wheelchair on Palau, Caroline Islands.

tional beliefs, customs, and culture. In many instances, the predominant, indigenous culture has embraced westernization and adopted or adapted cultural practices. This is seen in changes to local diet, increased health/rehabilitation concerns, Western-style homes, cultural stigmas, and the general adoption of Western behaviors. The island cultures are adapting to the demands of an industrial age, cash-based economies, and the consequences of population growth. Except for Hawaii and possibly Guam, the current lack of developed economic infrastructure continues to hinder growth and development at all levels in the Pacific.

Critical issues for individuals with disabilities include limited human and medical services, community inaccessibility, cultural beliefs and practices, isolation, external economic influences and limited resources. In many cases, medical services are provided by the government, and the availability and range of services may be limited. The needs of persons with disabilities living in the Pacific compete against needed infrastructure services such as road construction, community development, communications systems, and general health service delivery (Heath, 1987). In most cases, human services, including vocational rehabilitation and mental health, are considered fringe benefits.

There has been limited technical assistance and/or research into the most feasible ways to accommodate the cultural and environmental needs of Pacific residents. Rehabilitation research has focused on medical research in the area of tropical and infectious diseases, treatments, and mental health. Although rehabilitation services are available to individuals with disabilities through special education, vocational rehabilitation (in selected entities), and public health, much of the service provision has been offered without prior evaluation or research to identify the needs and expected outcomes. Rehabilitation service has been developed based on mainland legislative mandates, requirements, and expectations, as well as mainland needs and assumptions.

The local service needs of each entity have been virtually ignored in the attempt to fulfill dictated standards and criteria for service provision. This situation is further compounded by requiring Pacific governments to develop new programs in response to U.S. Congressional mandates without benefit of the technical assistance needed to implement these programs. The significant challenge is to ensure that basic services keep pace with the growing needs and future changes in the Pacific.

The rehabilitation needs of individuals with disabilities in the Pacific are unique, diverse, and specialized; issues critical to quality of life in this area need to be addressed and much more must be done here in rehabilitation service provision, research, education, and training. 

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Developing a VR Program on the Tohono O'Odham Reservation

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Two primary beliefs stand behind the drive to develop vocational rehabilitation services:

- Everyone, regardless of his/her disability, can learn to be a productive, contributing member of the community.
- Paid work can be as therapeutic for one's recovery and stability as medications and counseling.

Beginning in 1994, an Indian Health Services grant funded the development of a day treatment program on the Tohono O'Odham Reservation for adults disabled with mental illness. The location chosen for this program is in a centrally located but rural area of the reservation. It is not widely known that the Tohono O'Odham reservation is the second largest reservation in the country and is the size of the state of Connecticut in land area. Since transportation is a major problem, as it is on most reservations, the program uses its mental health technicians to provide transportation to and from the program 4 days a week. Although everybody does a lot of driving, this setup allows for regular monitoring of each member's residential situation.

The day treatment program has been named *Tas Tonlik Ki* (House of the Rising Sun) by the members and provides educational, social, and recreational activities as well as individual and group counseling, arts, and crafts, cultural activities, substance abuse groups, talking circles, and community activities.

The day treatment program is based on a psycho-social rehabilitation model which is guided by four major principles:

1. An emphasis on *client choice*—the active involvement of clients in making



Members Wilfred Antonio (left) and Gerald Santos notch a beam for a ramada being built for an elderly tribal member.

decisions regarding their rehabilitation plan and the activities of the clubhouse.

2. An emphasis on *strengths and wellness* rather than focusing solely on symptoms and deviances.

3. An emphasis on *social and community integration*.

4. An emphasis to *foster relationships with service providers* that practice partnerships and advocacy.

Tas Tonlik Ki has a rich and varied daily routine of activities for members, but it did not have a vocational rehabilitation component until 1996.

In September 1995, the regional office of the Rehabilitation Services Administration, Arizona Department of Economic Security, published a *Request for Proposal* to develop vocational services for people with disabilities living in the rural areas of southeastern Arizona. Desert Survivors, a nonprofit human service agency in Tucson, offered to write a proposal for the *Tas Tonlik Ki* project

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that would create paid work opportunities and develop a job training program that was culturally and environmentally appropriate for the tribal members. Since the directors of Desert Survivors have a long history of developing human services on a number of reservations in the Southwest and the tribal support for this project was unanimously approved, the state VR agency generously committed to developing vocational services for the disabled tribal members of the Tohono O'Odham Nation.

This was a great example of bundling services, i.e., combining differently funded programs for persons with disabilities to increase the scope and range of services and interventions valuable to the therapeutic goals of each individual client.

The initial quest for paid work was based on the strengths, skills, and preferences of the participating members of Tas Tonlik Ki. A flyer entitled *We are Looking for Work* was the result of a few community meetings with the program members voicing their experiences and preferences for the kinds of work they would like to do in the community. We then distributed this flyer around Santa


Rosa and quickly received requests to build fences and ramadas, dig outhouse pits, do landscape and cleanup work, patch adobe homes, gather firewood, and bake bread and tortillas. The cost of each job is negotiated by the person or family requesting the work and the vocational coordinator who represents the Tas Tonlik Ki members. The members must agree to complete the work for the negotiated price before the work begins. This type of work solicitation is a valuable resource for the community in that there are many people, especially the elderly, who do not have the extended family, energy, or time to get necessary jobs completed; as in most rural areas, there are few if any businesses to do this type of work.

Another paid work activity that produces a multitude of gratifying results is our once a week "Meals on Wheels for the Elderly." Tribal Services for the Elderly connected Tas Tonlik Ki with a national charitable organization that sponsors nutritional programs on reservations and they provide the funding for our members to cook and deliver a nutritional and often traditional meal for 14 elderly tribal members who are shut-ins.

These examples of job creation are wonderful opportunities for the vocational rehabilitation clients in Tas Tonlik Ki to earn money, develop practical skills, and demonstrate to everyone that they are contributing, productive individuals who make their community a better place to live. The rise in self-esteem of the members involved in these activities has been reported by family members and staff alike, and objective measures of success such as regular attendance and time on task also reflect positive results.

There are many other directions that our job creation efforts are going. We are expanding our garden so that we can grow produce for our members as well as sell excess produce to the community and we are adding a nursery to sell native plants, shrubs, and trees to the local communities. We recently put in a bid to do landscape installation for a newly completed school on the reservation and we are assisting a tribal member who is trying to start a carwash that will eventually employ some of our members.

Most reservations do not offer many job opportunities in general and for those with disabilities, practically none. The reality is that there are many services and products that are lacking on reservations that tribal members are willing to pay for and on these needs a viable rehabilitation program can be built.

Creating employment opportunities on reservations and in rural areas requires a sensitivity to clients' skills and interests and the immediate needs of the surrounding community. Funding for vocational rehabilitation programs is available through a variety of sources and one does not need to wait for a Section 130 grant to get started. The benefits that a vocational rehabilitation program can provide for people with disabilities and their communities are astounding; please find out for yourself. 



Tas Tonlik Ki member Thomas Lewis, who lives in the San Xavier District, works in a vegetable garden.

For more information, consultation, and technical assistance, please contact Joseph Lachowicz, Ph.D. Desert Survivors, Inc., 1020 W. Starr Pass, Tucson, AZ 85713. Telephone: (520) 884-8806.



The National Family for the Advancement of Minorities with Disabilities: New Leadership for a Changing World

*Cynthia L. Ingraham
John Sanford, Esq.
William K. Holley, Jr.*

For years, the lack of multicultural competence of service providers working in the fields of vocational rehabilitation (VR) and special education has served as a source of frustration for many minority people. Heppner and O'Brien (1994) agree that many minority clients who have sought services over the years have given up due to the lack of cultural sensitivity on the part of VR professionals. The Smith-Fess Act of 1920, which is the foundation for the rehabilitation system that we all know today, was established to address the rehabilitation needs of non-military persons with physical disabilities (Wehman & Moon, 1988). Since that time, the rehabilitation system has changed and evolved into what is today the most comprehensive inclusive service delivery system ever. The 1992 Amendments to the Rehabilitation Act address the needs of this everchanging American society and make provisions for the anticipated growth in the consumers who will eventually seek rehabilitation services.

Unlike previous years, the rehabilitation system is now very stringent about its policy which states that professionals are not to create, draft, or implement a consumer's service plan without the consumer's input. Additionally, the composition of the professionals

within the field has changed. More often, minority persons and persons with disabilities are among those professionals working cooperatively with the consumer to design the most appropriate and beneficial service plan to address needs of assistive technology, employment training, remedial education, and independence. Despite the increase in the presence of persons with disabilities and minority persons in the human services fields, there still remains a definite need for swift, precise, and deliberate efforts to further enhance the membership of such persons into this profession. The increasing overrepresentation of minority persons in special education programs has direct impact on the underrepresentation of minority persons who are in decision-making positions in the field of education (MacWilliams, 1994). The 1992 Amendments, in addition to efforts to work with Historically Black Colleges and Universities to recruit minorities into the field, have devised an initiative to address the cultural diversity issues of consumers. This initiative's objective is not only to increase the number of persons from diverse cultures who receive appropriate services from human services agencies, but, more importantly, to increase the number of minority persons with disabilities who will be employed in the field. The lack of understanding of the majority of professionals concerning the cultural needs and customs of clients attempting

to access the service delivery system often created what Wrenn (1962) coined the "pretended reality." This reality, which is based on the majority counselor's stereotypical understanding of the client's culture, has led to many consumers abandoning the rehabilitation system or never fully realizing their actual potential due to inappropriate training and low expectations. It is anticipated that with the increase in the number of professionals from minority backgrounds entering the field of human services, who themselves have a disability, the specific needs of the minority client will be met. The barriers created by culture and disability will be lessened and eventually eradicated.

In an effort to capitalize on the new initiatives set forth in the 1992 Amendments, a group of concerned minority, disabled, and highly motivated professionals convened in Washington, DC, in February 1994 to address the issue of the overrepresentation of minority persons and persons with disabilities in special education programs. Underrepresentation of this population in the more

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competitive and progressive employment training programs and positions was also discussed. This group of professionals acknowledged, as does Lim et al. (1994), that, historically, the American educational system has focused on the Anglo-American and has not given comparable consideration to the diversity of the population within the school system. It is then not surprising that many minority persons and persons with disabilities have found it challenging at best to succeed in the mainstream. This group of more than 150 professionals from across the country participated in a National Summit, titled "Beyond Rhetoric: Fulfilling the Promise of Full Partnership for Traditionally Underrepresented Minorities with Disabilities," sponsored by Congressman Major Owens, then Chairperson of the Subcommittee on Select Education and Civil Rights; the Congressional Black Caucus; and Congressional Black Caucus Spouses. Professionals from University Affiliated Programs and from Parent Training and Advocacy Programs, professionals who themselves had disabilities, and family members and friends of minority persons with disabilities discussed the needs of this group of consumers. Following the 2 days of meetings, a group of professionals remained in Washington to form a new group that recognized the need for unity to properly and effectively devise innovative strategies to ensure the enhanced growth and development of all minority persons with disabilities. The National Family for the Advancement of Minorities with Disabilities—"the Family"—is symbolic of the kinship that many minority persons as well as persons with disabilities experience as common members of a traditionally underserved and underrepresented group. The mission of the Family is one of leadership. John Sanford, Esq., chairperson for the Family, states that the implementation of a comprehensive range of strategies to ensure, protect, promote, and advance the legal, economic, and human rights of racial/ethnic minority persons with disabilities and their families at the national, state, and local levels is paramount.

Many minority persons and persons with disabilities have found it challenging at best to succeed in the mainstream

An additional goal of the Family will be to provide minority persons with disabilities and those nondisabled persons from ethnic and cultural minority groups with opportunities to participate in mentoring programs as a means of increasing the number of professionals that are trained, qualified, and available to work with a rapidly growing diverse constituency. The Family has begun this process of networking and mentoring by reaching out to establish partnerships with historical civil rights organizations, disability advocate associations, grassroots organizations, and other human service organizations that promote services to minority persons with disabilities. The Family is currently in the process of establishing collaborative efforts toward building partnerships with the Consortium for Citizens with Disabilities, President's Committee on Mental Retardation, National Independent Living Center, Rehabilitation Services Administration's National Multicultural Concerns Committee, National Council on Disability, ASPIRA, NAACP, the National Urban League, Inc., and various local grassroots organizations throughout the continental United States.

This grassroots effort has already begun to take shape in various parts of the country. In Omaha, Nebraska; Minneapolis, Minnesota; Wichita, Kansas; and St. Louis, Missouri, efforts are un-

derway to work cooperatively with the National Urban League, Inc., to promote the cultivation of a regional network of disability advocacy leaders who are members of minority groups with disabilities and their families. Additionally, efforts will include engaging traditional civil rights organizations in the cultivation of these disability advocacy leaders and, by doing so, establish the organizational presence of these groups as national partners in the disability advocacy rights movement. Planned activities include involving members from the disability community and their families as key participants in disability rights activities and designing and implementing a comprehensive information dissemination program that will assist public policy-makers, community advocacy groups, and traditional civil rights organizations in cultivating racial and ethnic minority group members with disabilities and families as leaders in national, state, and local disability advocacy efforts.

The Family has begun this process . . . by reaching out to . . . historical civil rights organizations, disability advocate associations, grassroots organizations. . . .

On September 17, 1995, during the Administration on Developmental Disabilities Commissioner's Forum, titled "Americans with Developmental Disabilities and Diversity: Opportunities and Justice for All," Earl Shinhoster, acting national director of the NAACP,




Guidance Counselor William Greene of the C. Melvin Sharpe Health School in Washington, DC, with some of his students who are preparing for the Paralympics in Australia in 2000.

stated that the NAACP is one organization that operates in some 2,200 communities across the country and is made up of men and women and boys and girls of every race, creed, and color and also includes people who walk straight and people who ride wheelchairs. Mr. Shinhoster also said that, while the NAACP is a single organization, the leadership has a willingness to join forces to work with the movement undertaken by the Family because the two movements are indeed one and the same.

The membership of the Family realizes that its mission creates a challenge for the civil rights organizations, traditional disability advocate associations, and minority individuals with disabilities and their family members. However, the true challenge includes the establishment of partnerships with

a focus on providing services and opportunities for minority individuals with disabilities and their families. In order for this goal to remain consistent with the proposed mission, the Family must gather information, solve problems, and make recommendations to appropriate bodies of leadership. The Family's goal cannot be accomplished if the objectives do not include the development of strategies to access the educational and rehabilitative services for minorities with disabilities, analyze and disseminate information about effective programs, identify professionals who are willing to serve as role models for minorities with disabilities, and sponsor annual summits to review with the partnership progress made on issues affecting minorities with disabilities.

The Family will be hosting the Second Annual Summit—"Linking Lives Through Partnerships"—in the fall of 1996. The summit will include a training institute on how to organize and build a national partnership for family members. The membership of the "Family" will be available to provide cultural sensitivity training to agencies serving minority persons with disabilities as well as participate in recruitment efforts to encourage minority youth to consider future career opportunities in the human services field.

The official publication of the National Family for the Advancement of Minorities with Disabilities, *The Family News*, was distributed in January 1996. The first edition of the newsletter is dedicated to the mission of the Family to improve the lives and conditions for each other and end discrimination based on disability, race, color, or creed through the dissemination of information. Professionals and organizations interested in obtaining additional information on the Family may contact: Office of the President, National Family for the Advancement of Minorities with Disabilities, P.O. Box 597, Okeanos, MI 48805-0597. 

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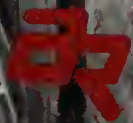
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AMERICAN Autumn 1996 REHABILITATION



**Spinal Cord
Injury**

Part 1 of 3



An Introduction to Spinal Cord Injury Issues for Rehabilitation Professionals

Fredric K. Schroeder

This issue of *American Rehabilitation* is the first of a three-part series that will explore the challenges and opportunities to be faced by individuals with spinal cord injury. In this issue—Part 1—the following topics are covered as they relate to spinal cord injury: “Quality of Life,” “Boston’s Community Medical Group and the Community Medical Alliance Health Plan,” “Facts, Figures, and Trends,” and “Spinal Cord Injuries Due to Violence.”

We are able to document the existence of individuals with spinal cord injuries as early as the ancient Egyptians some two thousand years ago. From that time until the Second World War, little progress was made in treating spinal cord injuries; thus, they were typically viewed as being incurable and as a death sentence since many individuals would die from infections secondary to their injury.

During the 1940’s, progress began to be made in understanding and treating spinal cord injuries. Much of this progress was the result of the rapid advances in the utilization of antibiotics. With antibiotics, the average life span of individuals with cord injuries began to approach that of nondisabled individuals. In the 1950’s, both medical and nonmedical programs focusing on the needs of individuals with spinal cord injuries were established and then rapidly expanded in the 1960’s. The 1950’s also saw many individuals with




injuries to the spinal cord resulting from the major polio epidemics. This spurred further research efforts focusing on the medical management of individuals with cord injuries.

The development of programs and services for individuals with spinal cord injuries in the 1960’s parallels the development of major national social, rehabilitative, and independent living programs in America. There were other forces at work, also. It was the time of rapid advances in television, civil rights, and medicine. It was the time for the “Great Society” initiative of President Johnson who persuaded Congress to create a number of social programs designed to improve the lives of the country’s citizens, including individuals with disabilities. It was, however, also the time of another war, the Vietnam War.

Out of the tragedy of this war was born the desire and commitment to treat fairly those who returned with serious injuries. Due to advances in medicine and improved battlefield medical management interventions, soldiers were able to survive injuries from which they would previously have died. Thus, many soldiers returned home with very severe disabilities, including spinal cord injuries.

The decade of the 1980’s witnessed the birth and rapid maturation of the disability rights movement as we know it today. It was during this period that key legislative ini-

tiatives were developed, such as the 1983 Rehabilitation Act Amendments, which added the Client Assistance Program, the Mental Illness Bill of Rights Act, the Civil Rights Restoration Act, the Air Carrier Access Act, and the Fair Housing Amendments Act, and culminated with the signing of the American’s with Disabilities Act (ADA) in 1990. The implementation of the ADA with its employment and access provisions has created an irreversible momentum for the removal of physical and attitudinal barriers that have denied individuals with spinal cord injuries full access to the benefits of American society and employment opportunities. With advances in these areas, related benefits for individuals with spinal cord injuries such as lever handles and other housing adaptations are becoming commonplace. 

AMERICAN REHABILITATION

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Boston's Community Medical Group and the Community Medical Alliance Health Plan

a national model of consumer-oriented, prepaid, managed care for independently-living persons with spinal cord injuries (SCI)

Boston's Community Medical Group (BCMG) was among the first primary care group practices to provide community-based continuous primary care to people with major disabling conditions; the first to rely upon nurse practitioners as primary caregivers, and one of the first to provide care on a prepaid capitated basis. With more than a thousand person-years' experience, BCMG has demonstrated that it is ethically and operationally feasible to 1) provide prepaid managed care to people with major disabling conditions; 2) share financial risk for that care with providers; 3) reinforce principles of independent living and consumer autonomy; and 4) assure high-quality clinical outcomes at reasonable costs.

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The *New Yorker* cartoon (April 1, 1996, p. 59) reproduced on the following page highlights a very serious contemporary concern: that prepaid managed care plans, like the hapless Humpty's HMO, ration resources, respond to consumer need only slowly and reluctantly, and, even then provide only a fraction of the services that consumers legitimately need. There are particular concerns about the effects of managed care upon people with major disabling conditions, including but not limited to spinal cord injuries (SCI). A person interviewed for a recent *New York Times* article (1996, January 15) on the effects of managed care upon people with AIDS said that his HMO—Health Insurance Plan (HIP) of New York—"came to seem less his ally than his enemy" (p. 1). Consumers, advocates, and healthcare professionals have made substantially the same argument about managed care and SCI. Indeed, many have argued that prepayment—and managed care more generally—is fundamentally incompatible with disabled persons' independence, autonomy, and highly complicated healthcare needs.

Boston's Community Medical Group's experience suggests otherwise; that whatever the problems of individual prepaid managed care programs, there is no fundamental incompatibility between prepayment and the social and healthcare needs of people with major disabling conditions. Throughout its 13-year history, includ-

ing 5 years' experience providing care on a prepaid basis, BCMG has maintained a consistent commitment to principles of consumer autonomy and independence, provider flexibility, and high-quality cost-effective healthcare.

In the current climate of growing interest in developing prepaid managed care programs for people with major disabilities and growing concerns about such programs' social, emotional, and medical costs, BCMG's goal is to become a model for cost-effective, socially responsible, consumer-oriented primary care.

Background: Managed Care and Disability

Historically, HMO's and other managed care providers have served employee groups and, more recently, the younger and relatively healthier Aid to Families with Dependent Children (AFDC) component of state Medicaid populations. They have had little interest and only limited experience with people with SCI or other major chronic disabling conditions, most of whom have received healthcare from public or private fee-for-service programs. Even insofar as HMO's have had experience with Medicare beneficiaries, analyses suggest that they have served healthier, more independent older adults, rather than nursing home residents, people with disabilities, or people with end-stage renal disease.

More recently, with growing concerns about the costs of medical care, and especially the costs borne by public programs (most notably, Medicaid, Medicare, and the Veterans Adminis-

tration), there is considerable interest in managed care programs as means of better organizing services and controlling costs. There is particular interest in managed care for people with SCI and other similar disabling conditions, because they require an extraordinary intensity of health services, because they rely heavily upon public payments, and because they account for a disproportionate share of health and social service costs.

Ethical Concerns about Prepayment

In response to this interest, there have been corresponding ethical and operational concerns about the appropriateness of managed care programs for high risk groups. As the author of the recent *New York Times* article noted: "Switching to a managed care network is wrenching for any patient, since it often requires a change of doctors. But it is particularly difficult for the chronically ill, since they have often developed close relationships with a collection of doctors, after trial and error" (p. 12).

There are particular concerns about managed care programs that entail provider financial risk: i.e., partial or complete fiscal responsibility for beneficiaries' healthcare costs if these costs exceed an established limit. Financial risk, critics argue, provides incentives to withhold or curtail services in the interest of profit. Managed care, they assert, can provide a rationale for providing fewer services to those who need more. Faced with threats and claims that imply that managed care means denial of service, some disabled consumers—including those with SCI—and their advocates argue that managed care programs cannot serve people with major disabling conditions, that such people have such great needs and such intimate familiarity with their own social and medical conditions they must therefore be free to make their own medical decisions, without managerial assistance, free of financial constraints.



"He's in an H.M.O. Get some of the King's horses and a few of the King's men."

Drawing by Leo Cullum; ©1996
The New Yorker Magazine, Inc.

Responses

In defense of risk assumption and prepayment, managed care advocates cite the historic struggle of people with disabilities confronting persistent barriers that prevent them from finding reliable, knowledgeable, and sensitive fee-for-service care: such impediments include architectural and transportation barriers, limited access to medical specialists, limited time with providers, and regulatory and fiscal restrictions on the development of flexible, responsive services. And, they argue that *only* prepayment provides the kinds of financial incentives and operational flexibility to respond quickly and appropriately to beneficiaries' complicated and rapidly changing medical, social, and psychological needs.

Managed care providers can assure prompt and predictable access to medical specialists and to mental health, counseling, and other services to treat or prevent alcohol or other substance

abuse. In contrast to fee-for-service providers, most of whom have strict regulatory limits on the kinds of services that they can offer and the speed with which the services can be delivered, providers in prepaid risk-based programs have extraordinary latitude. For example, they can employ nurse practitioners, physician's assistants, and other nonphysician providers; provide home care services to people who have difficulty reaching offices; pay reasonable rates for medical specialists, skilled nursing facilities, or home providers to reflect the fact that disabled persons may require more time or

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Katrina Pullen with nurse practitioner Margaret Paustian.

greater intensity of services. They can develop self-help or family assistance programs, provide or arrange special transportation services, or selectively and expeditiously purchase or rent equipment for their patients' short- or longer-term needs. They can do these things, they say, mainly because they can reduce the use of hospital-based services—both inpatient and outpatient—and allocate the funds saved from deferred hospital admissions or reduced hospital stays to other, more appropriate needs.

In summary, in return for the assumption of at least some degree of financial risk, providers of prepaid managed care have substantially greater flexibility than their counterparts whose practices are governed by Medicaid regulations and private health insurance contracts. They argue that such flexibility is especially important for people with major disabling conditions: people who are vulnerable to a wide range of highly prevalent, morbid, or lethal secondary complications, such as decubitus ulcers, autonomic dysreflexia, and respiratory and urinary tract infections (RTI's and UTI's), that require prompt, decisive, and creative provider response.

Boston's Community Medical Group: Prepaid Managed Care for People with Major Disabling Conditions

The program which later was to become BCMG was established in 1982 as the Independent Living-Primary Care Program, a component of the Urban Medical Group (UMG). UMG, in turn, had been established in 1978 by a group of Boston area physicians, nurse practitioners, and physician's assistants—"a rag-tag band," according to a close professional friend and observer—to provide responsive, continuous primary care to Boston's inner city nursing home residents and frail homebound older adults, "people that the rest of the profession didn't seem to care about." To these ends, and despite considerable financial and professional disincentives, UMG stressed the need to provide care in home and community settings, including nursing homes, rather than inpatient settings, hospital outpatient clinics, and emergency rooms.

This unique care program was a cooperative venture among UMG, Boston's Beth Israel Hospital, and the Boston Center for Independent Living

to apply these same principles and to provide these same benefits to younger adults living independently in inner city settings with such major disabling conditions as SCI, cerebral palsy, head injury, and both stable and degenerative neurologic disease. Speaking of the IL-PCP's founder and motivator—the late Dr. Marie Feltin¹—a colleague notes that "she didn't really fit into the structured world . . . she liked to be able . . . to see people in their homes." Home visits, according to Dr. Feltin, allowed more time for questions. Another colleague said that she and other BCMG clinicians understood "the limits of medicine" and the value of "sitting and talking." Making a home visit, Dr. Feltin said, means that "you're on the patient's turf," subject to his or her schedule, and exquisitely sensitive to his or her circumstances and needs. Though "this makes some physicians feel insecure," it helped her, her professional colleagues, and, most significantly, their patients, to develop an effective trusting relationship. According to a professional colleague—a nurse practitioner—BCMG staff visits "never really felt like it was the doctor coming to see patients. It was Marie coming to see her friends."

The program's goal was to meet the healthcare needs of adults with severe disabling conditions in ways that would support their independence and autonomy and empower them to be active participants rather than passive recipients of care: that emphasized their "capacities, above all, even if they were handicapped." Typically, people living independently with SCI would use emergency rooms for the evaluation of such acute problems as fever, urinary tract infections, and respiratory infections. Often, they would lie for hours on stretchers or gurneys awaiting treatment, and would subsequently be referred to specialty clinics for followup care. They were skeptical of the traditional medical model that encouraged dependency and often failed to respect their choices. Frustrated by a system of care that relied heavily on hospital-based services, specialty care, and emergency rooms that offered little in the

way of coordination or consistency of care, they wanted primary care that would provide them with accessible, continuous, personalized, responsive, and respectful care. And the IL-PCP met their needs.

One long-time BCMG consumer said that, in contrast to previous physicians, who had intimidated and mystified her, Dr. Feltin was "just normal." Another, with a high-level SCI, added that she and her colleagues were "not part of that structure, that medical construct that always treated me like an object . . ." He continued by observing that for people with major disabling conditions, illness is bad enough, but "going to the doctor just becomes a nightmare." In this context, he said, there was considerable reassurance "knowing that they (i.e., doctors and nurses) are going to come to your home, and that it's OK . . . that it's not a problem . . . that you're sick."

BCMG Becomes Independent of the University Medical Center

In 1988, Dr. Feltin and Mary Glover established Boston's Community Medical Group (BCMG), a separate and autonomous program with an exclusive focus upon the care of people with severe physical disabilities. They moved the program's operations to the Boston University Medical Center to cultivate a growing collaboration with the Department of Rehabilitation Medicine and the New England Regional SCI Center. The program has grown by voluntary enrollment to 179 members.

Home visits are made frequently to monitor chronic conditions and to provide urgent care in the home rather than in the office or emergency room.

Program Operations

Every consumer enrolled in BCMG has a primary physician who provides medical management and coordination and who is available to both nurse practitioners and consumers for advice and consultation, 24 hours a day, 7 days a week. At weekly team conferences, the clinicians discuss cases involving active problems or those scheduled for periodic review. The primary physician is the admitting physician of record; he or she coordinates all inpatient care.

In outpatient settings, nurse practitioners have central roles in both direct patient care and case management. Each nurse practitioner follows 40-50 patients, usually clustered geographically. For each consumer, she performs a comprehensive initial assessment; she is the first to respond to new problems. Home visits are made frequently to monitor chronic conditions and to provide urgent care in the home rather than in the office or emergency room.

As the case manager, the nurse practitioner coordinates all needed services, such as mental health, home health, rehabilitation therapies, and social services. The nurse practitioner also works collaboratively with the physician and hospital staff to coordinate discharge planning. The nurse practitioner supplements home visits with frequent phone contact to answer questions and offer reassurance, guidance, and support.

The case management function is essential to the role of the nurse practitioner in that it allows for the integration of clinical decision making and the management of resources. Once a problem has been identified, the nurse practitioner can immediately discuss the treatment options with the patient and arrange for their implementation. In the capitation model, the nurse practitioner is empowered to mobilize resources such as home infusion, home health, private duty nursing, and home respiratory care. The nurse practitioner can assess and treat more quickly than a less knowledgeable or less empowered case manager.

A recent example illustrates the range and flexibility of BCMG nurse practitioners' roles. John, a 36-year-old man with C5-6 quadriplegia as the result of a spinal cord injury sustained 20 years ago, recently developed symptoms of a urinary tract infection; he immediately called BCMG's 24-hour call service. His physician recommended an emergency room evaluation, because John sounded quite ill and because it was 5 a.m.

John refused and requested a home visit by his nurse practitioner that morning. The nurse practitioner made a thorough assessment and discussed the various treatment options with John. He continued to oppose hospitalization and requested treatment at home. Based on her medical assessment, her close personal relationship with John, her knowledge of his capabilities and support system, and her ability to mobilize appropriate medical therapies, the nurse practitioner agreed. She drew blood, obtained a urine culture and blood cultures, and initiated oral antibiotic coverage immediately. After obtaining preliminary lab data and consulting with the primary physician, she made a referral for home infusion and ordered intravenous antibiotics and fluids.

John was assessed daily and responded well to treatment. This illness easily could have resulted in a 5- to 7-day hospital stay without this coordinated approach to care.

Ultimately, it is the trust that develops between provider and patient that is the key element to this successful partnership. The home visits enhance communication and a relationship of equality which contributes to a more effective and empowering treatment of the patient.

Finance

Despite the enthusiasm of both consumers and providers for the model, it quickly became evident that traditional reimbursement mechanisms were inadequate because these placed little value on home visits, provided correspondingly low reimbursement for home visits, and offered neither

Table 1
CMA Eligibility Criteria

Spinal Cord Injury

with functional quadriplegia, quadriparesis, or tri paresis.

Traumatic Brain Injury

with functional quadriplegia, quadriparesis, or tri paresis

Spinal Cord Injury

with functional paraplegia, AND secondary complications including recurrent urosepsis, OR recurrent bacterial pneumonia, OR persistent decubitus ulcer, OR Substance abuse.

Degenerative Neurologic Illness

with functional quadriplegia, quadriparesis, or tri paresis

Cerebral Palsy

with severe spasticity OR functional quadriplegia

Other Neurologic Condition

with functional quadriplegia, quadriparesis, or tri paresis

Any Other Condition

requiring a minimum of 10 hours per week of personal assistance service for activities of daily living (ADL's) OR a minimum of 14 hours per week of personal service to meet ADL and instrumental ADL needs.

recognition of nor reimbursement for the nurse practitioners' expanded role. In fact, nurse practitioners initially were reimbursed through independent living centers as "skills trainers."

Beginning in 1982, a special arrangement was negotiated with Massachusetts Medicaid to reimburse the UMG at its cost on a fee-for-service basis for nurse practitioner, physician, and physical therapy home and office visits. The unique system emphasized a nurse practitioner/physician team approach, home-based services, 24-hour availability, and direct, private admission to the Beth Israel Hospital: all on a fee-for-service basis.

BCMG's fee-for-service arrangement with the Massachusetts Medicaid program continued until April 1992, when Community Medical Alliance (CMA), an independent organization with close historic and operational ties to BCMG, entered a prepaid capitated contract with Massachusetts Medicaid.

Under the terms of this arrangement, the Massachusetts Medicaid program pays monthly capitations to CMA, which, in turn, contracts with BCMG to provide a comprehensive package of services to people who meet clinical criteria described in Table 1. For those who meet these criteria, enrollment is voluntary.

With this capitation, CMA, through BCMG, agrees to provide a comprehensive set of services described in Table 2. These benefits represent all Massachusetts Medicaid benefits, except oral pharmacy, dental care, eye glasses, non-emergency transportation, and personal care attendant (PCA; also known as Personal Attendant [PA]) services, for which Massachusetts Medicaid continues to pay on a fee-for-service basis.

For enrollees with physical disabilities, most of whom had been BCMG's fee-for-service patients before 1992, the monthly medical service capitation was \$1,997 for those who were eligible for

Medicaid only. For those dually entitled to Medicare and Medicaid, the monthly capitation between 1992 and 1995 was \$432. In 1995, the monthly capitation for those eligible for Medicaid only dropped to \$1,680, while that for those dually entitled rose to \$772.²

Effective April 1995, on the basis of a National Committee for Quality Assurance survey, the Massachusetts Medicaid Program authorized enrollment in CMA (and its affiliated clinical programs, including BCMG) by any person with a disability who receives Social Security Insurance (SSI). To this end, CMA receives a monthly capitation, currently under negotiation, of approximately \$446.07, for a range of services that is as comprehensive as those provided to those with severe disability and AIDS. Once approved, this contract will allow BCMG to offer prepaid managed care to virtually all Massachusetts Medicaid beneficiaries with SCI, not just those who meet the highly restrictive eligibility criteria in Table 1.

Current Status and Projections for Growth

Since its inception, BCMG, through CMA, has provided care to 254 peo-

Table 2
CMA Benefits

- Primary care
- Medical specialty care
- Acute hospital inpatient and outpatient services
- Emergency services
- Home healthcare
- Private duty nursing
- Durable medical equipment
- Home infusion therapy
- Mental health
- Substance abuse treatment
- Chronic hospital
- Adult day health
- Adult foster care
- Laboratory and x-ray
- Case management

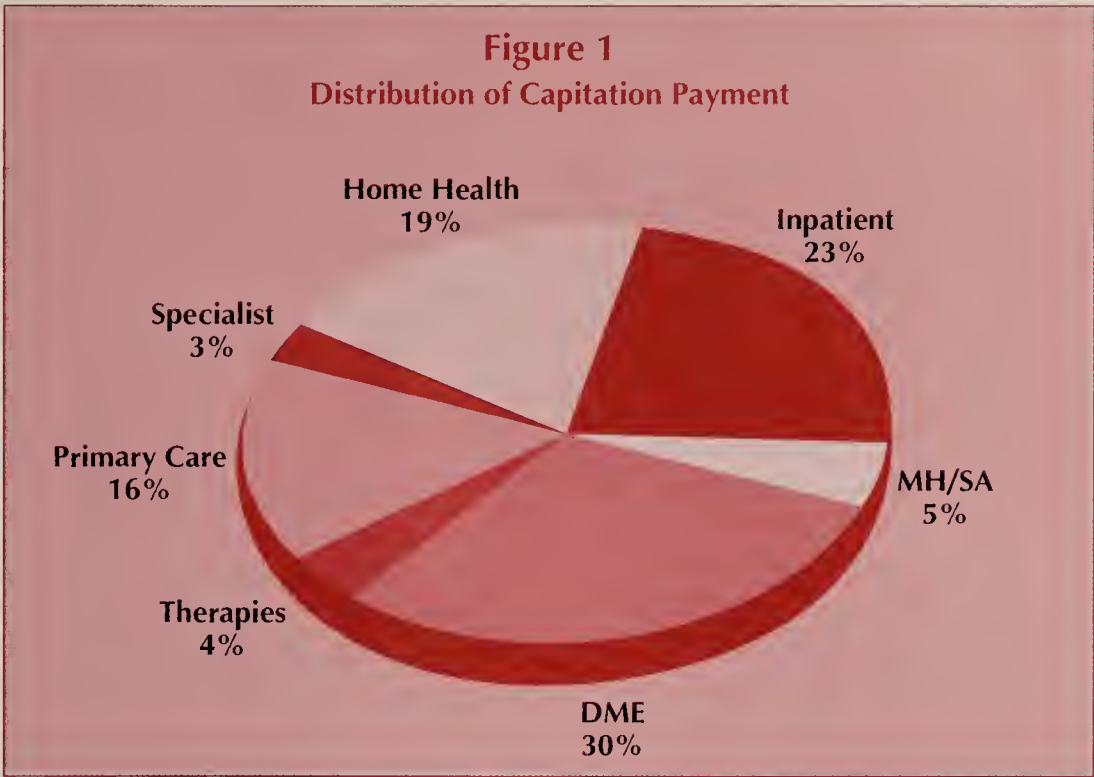
ple; and in January 1997, the prepaid caseload is anticipated to be 205 individuals with major disabling conditions, of whom 35 percent are female and 20 percent are members of minority groups. Some 55 percent fall within the 15–39 age range; 10 percent are 60 or older. Forty-two per cent of BCMG clients have stable neurologic disabling conditions, most notably, cerebral palsy; 28 percent, cervical-level SCI; 11 percent, degenerative neurologic conditions; 7 percent, traumatic brain injury; and 9 percent, paraplegia with the complications noted. More than three-quarters receive the services of one or more personal care assistants.

To meet their needs, BCMG employs 1.3 full-time equivalent physicians, 4.0 full-time equivalent clinical nurse practitioners, 0.4 full-time equivalent administrative nurse practitioner, and 4 full-time equivalent administrative and clerical staff.

Use of Services

Figure 1, which is based upon 372 person-years experience—between April 1, 1992 and March 31, 1994—shows the per capita monthly expenditures and proportion of total expenditures for each of 9 categories of healthcare. There are several remarkable features:

- The proportion of expenditures for inpatient services is relatively small, less than a quarter of all expenditures. The corresponding figure for Massachusetts Medicaid beneficiaries with major disabling conditions who receive care on a fee-for-service basis is 55 percent.
- The proportions for durable medical equipment (DME) and supplies, in contrast, is quite high, higher than inpatient services. The evaluation and development of the DME program has been one of CMA's greatest challenges. Consumers have developed strong loyalties and highly personalized relationships with vendors over the years. Often, they are extremely reluctant to change providers, even if CMA or BCMG feel that other providers can provide equal or greater value at lower cost.



Access to appropriate equipment and supplies and to prompt, efficient, and reliable wheelchair repairs is integral to independent living. BCMG has hired a DME coordinator to organize services by acting as a liaison between enrollees, vendors, and clinicians to assure prompt delivery of services while avoiding duplication. Based on a survey of enrollees, preferred vendors are being approached for contracting that will include specific service expectations as well as negotiated fees and volume discounts. All requests for wheelchairs must be evaluated by a physical therapist in the seating clinic. Costs are expected to rise despite these efforts, however, with the explosion of technology currently available in the form of environmental control units and computer assistive technology.

- The proportion of expenditures for medical specialist services also is relatively small; the ratio of primary care to specialist services is more than 5:1, and Table 3 shows that nurse practitioners rather than physicians are the main providers of primary care services; the ratio of nurse practitioner to primary physician expenditures is more than 2:1. BCMG patients experience about 1.2 primary care visits per member per month (PMPM), about 15 visits

annually. Of these, 87 percent are home visits and 89 percent are provided by nurse practitioners.

The mental health and substance abuse benefit has no limits; yet, the service utilization is quite small. The thought, which is currently under review, is that much of the needed supportive counseling and crisis management is provided directly by the primary care team during day-to-day interactions, reducing the need for more formalized mental health services.

In summary, BCMG's experience defies a number of prevailing prejudices about continuing care for people with major disabling conditions. It is home- and community-based, rather than based in institutions. It relies heavily upon primary care providers rather than medical specialists. And, most notably, in contrast to conventional wisdom that characterizes nurse practitioners as "physician extenders," BCMG's nurse practitioners are truly primary caregivers, closely supported by primary care physicians (internists) with only occasional use of specialty medical care.

Despite BCMG's progress to date with expanding opportunities for people with disabling conditions to participate in comprehensive, coordinated,

Table 3
BCMG Visits: January 1994–January 1995

Visit Type	Total	Percent	PMPM
MD	285	11	0.13
NP	2,372	89	1.08
Office	358	13	0.16
Home	2,299	87	1.05
Total	2,657	100	1.21

consumer-oriented primary care, there remain several areas of unmet need.

BCMG's providers have refocused dollars from specialty and hospital-based services to a more personalized, individualized approach, without apparent compromise of quality of care. What are the boundaries for using medical dollars to assist people with disabilities in gaining access to interventions that would maximize function and support healthy life styles? Such services as computer-assisted communication devices, recreational programs, and access to fitness centers could provide tremendous enhancements of both social and medical well-being. So could such services as additional physical therapy or acupuncture to relieve spasms and pain. However, such services traditionally have not been considered medically necessary. Determining the limits of medical benefits and identifying funding sources to provide them are major challenges for CMA and BCMG.

Preliminary Studies of BCMG's Impact on People with SCI

An analysis of BCMG's experience with skin care and the prevention of pressure ulcers, undertaken as part of its routine quality assurance program and described in detail in a recent paper, shows that prepaid managed care may reduce the morbidity, hospital admissions, and medical care costs associated with one of the most pervasive, destructive, and costly consequences of major disabling conditions. If this finding is borne out by larger

and more definitive studies, it will have special relevance for people with SCI.

How did this happen? Though the numbers are small and the experience limited, these data, supplemented by interviews with BCMG's managed care providers, suggest that the most significant difference is "clinician empowerment": i.e., the ability of a nurse practitioner or physician with primary responsibility for the care of a person with SCI or other similar major disabling condition, to *order* rather than *request* interventions. Some such interventions entailed the use of durable medical equipment: for example, cushions or mattresses. Others entailed admissions to chronic disease hospitals or skilled nursing facilities. However, whatever the interventions, once they

had decided upon them, BCMG nurse practitioners and physicians were able to assure that they were applied without delay. This empowerment appears not only to reduce numbers of admissions for the management of pressure ulcers; it also appears substantially to reduce numbers of surgical procedures, average length of stay, and associated costs.


BCMG and the Refinement and Dissemination of the "Boston Model" of Prepaid Managed Care

From the program's inception, BCMG staff have recognized the importance of research for purposes of evaluation and quality improvement as well as a means of disseminating their experience to healthcare providers, consumers, and community agencies concerned about the quality and costs of healthcare. Working with researchers from the Boston University School of Public Health (BU/SPH), they have participated in special studies of such topics as hospitalization and the use of other medical care services; temporary disability; alcohol, tobacco, and cannabis use; and the effectiveness of managed medical care. There are now plans to work with BU/SPH and with Boston Medical Center's Model Spinal Cord Injury Center to refine a skin care assessment tool.



Nurse practitioner Carol Baumgarten with Peter Wong.

In the same context, and working with the same two organizations, there also are plans to undertake a prospective evaluation of the effects of prepaid managed medical care for people with SCI. This evaluation will be concerned with a wide variety of clinical, social, and psychologic outcomes, including, but not limited to, skin care.

More recently, BCMG staff have been active participants in efforts by BU/SPH's Medicaid Working Group, a project funded by the Pew Charitable Trusts and the Robert Wood Johnson Foundation, to help selected states develop prepaid managed care programs for Medicaid SSI beneficiaries. To this end, BCMG will continue to evaluate and improve its services in order to serve as a model for other similar programs in different locales. 

Acknowledgments

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Notes

1. Dr. Feltin died November 1994. The quotations that follow are taken from a testimonial film.

2. By way of comparison, CMA's capitations for people with AIDS are \$4,486.60 and \$1,554.24, for those who are and are not Medicare beneficiaries, respectively. All rates are subject to periodic review.

3. Forty-seven people continue to receive care on a fee-for-service basis, either because they are not eligible for Medicaid or because they do not meet the clinical criteria noted in Table 1.

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Spinal Cord Injuries Due to Violence

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Jeffrey Cressy
Rodney H. Adkins, Ph.D.

Interpersonal violence in the United States has reached epidemic proportions. The severity of the problem is such that the Centers for Disease Control and Prevention has created an official definition of violence: "...the threatened use of force or power against another person, against oneself, or against a group or community that either results in or has a likelihood of resulting in injury, death, or deprivation" (Rosenberg, 1994).

Every 2 years more people are killed by firearms in the United States than the total number of U.S. soldiers killed during the Vietnam War (*The World Almanac and Book of Facts*, 1993; Federal Bureau of Investigation [FBI], 1991-1992). Each day, an average of 65 people in this country die from interpersonal violence, and more than 6,000 are physically injured (Bureau of Justice Statistics, 1992; Harlow, 1989). During the decade of the 1980's, more than 215,000 people died and more than 20 million sustained nonfatal injuries from violence (Bureau of Justice Statistics, 1988; 1989; 1990). With approximately 10 homicides per 100,000 people per year, America's homicide rate ranks fifth in the world and first among industrialized nations (Prothrow-Stith, 1990). Homicide is now the third leading cause of death in the workplace (Stout, 1996).

Young men are disproportionately represented among perpetrators and victims of violence. During the 1980's, more than 48,000 people were murdered by youths between the ages of 12 and 24 (FBI, 1990). According to the

Centers for Disease Control and Prevention (1993), young people are the only group whose death rates have increased in the last 20 years, and most of those deaths were due to violent injuries or trauma. The homicide victimization rates for American males 15 to 24 years of age are eight times higher than those in the next highest country, Italy (Fingerhut & Kleinman, 1990). Among those aged 15-19 the 1989 homicide rate was 83.3 per 100,000 population for African-American males compared to 7.5 for non-Latino white males (Reiss & Roth, 1993, p. 256). Homicide is the number one cause of death among young Afro-Americans (O'Carroll, 1988).

Violence is not just a criminal justice or law enforcement problem; it can and should also be treated as a public health problem. Of all homicides, more than 50 percent of the victims knew their assailants; 47 percent of homicides are caused by arguments, whereas only 15 percent occur during the commission of another crime (Prothrow-Stith, 1990). Studies of victims reveal that alcohol was present in approximately 50 percent of the cases (FBI, 1981). The risk of becoming a victim of a nonfatal violent assault in the United States was three times greater for persons from families with incomes below \$7,500 than those with incomes above \$50,000 (Bureau of Justice Statistics, 1992). Such characteristics which allow identification of at risk populations give hope for the chance of applying public health prevention strategies and intervention before the violent act is committed.

While we speak of violence in generic terms, violence associated with firearms makes up the largest part of the problem. Firearms are used in almost 70 percent of all homicides (FBI, 1994). In



Single gunshot wound to L1-L2 area of the spine.

California, homicides by firearms are now the leading cause of injury deaths and were expected to be so nationally by the year 2000 (California Department of Health Services, 1992), prior to the easing of national restrictions on vehicle speed limits. There are more federally licensed gun dealers in California than there are McDonalds hamburger outlets.

With over 200 million firearms in this country, it is believed that firearm availability is associated with increased death and injury (Wintemute, 1987). In 1990, more teenagers died from firearms than all natural diseases combined (Mercy, 1993). The lifetime costs of all firearm related injuries occurring in 1990 was estimated to be \$20.4 billion (Max & Rice, 1993).

However, data related to the numbers of nonfatal firearm injuries compared to fatalities have been unreliable and difficult to collect. Estimates range between 2.6:1 to 7:1 (Annest, Mercy, Gibson, & Ryan, 1995; Rice, McKenzie, & Associates, 1989). There is no estimate of how many of these injuries result in spinal cord injury. Data also indicate that persons who survive a nonfatal injury are more likely to subsequently sustain a future fatal injury (Committee on Adolescence, 1992).

These trends and statistics are extremely disturbing. Many people think the United States is mired in a "Culture of Violence," where violence is increasingly accepted as a means of settling disputes and is glorified in an unacceptable manner. Spinal cord injuries caused by violence are a catastrophic by-product of this culture.

Violence and Spinal Cord Injury

As indicated above, epidemiologic data on nonfatal injuries is not readily available and detailed epidemiologic data on spinal cord injury is less available, with the exception of data from the Model Spinal Cord Injury Systems Program sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR). The Spinal Cord Injury Model System Database maintained at the National Spinal Cord Injury Statistical Center in Birmingham, Alabama, contains information on more than 14,000 new cases of spinal cord injury.

Within this database, the percentage of persons who have sustained spinal cord injury due to violence has risen dramatically. During the period 1973–78, violence accounted for 13.3 percent of cases entered into the database; in 1979–82 it accounted for 15.1 percent; 1983–86, 17.2 percent; 1987–90, 20.8 percent; and 1991–94, 30.4 percent (National Spinal Cord Injury Statistical Center [NSCISC], 1994). While this percentage shift may be partially due to a decrease in injuries due to motor vehicle crashes, an increase in injuries caused by firearms that has accounted for 88 percent of the violence related

spinal cord injuries is also evident (Stover, DeLisa, & Whiteneck, 1995).

Violence is more prominent in facilities drawing from urban versus rural catchment areas. In the urban facilities the percentages of injuries due to violence ranged from 21.1 to 50.0 percent; in the rural facilities the range was 6.6 to 21.2 percent (NSCISC, 1994).

The most prominent demographic difference between violence related spinal cord injuries and those related to other causes is in the ethnic distributions of those injured. Those injured by violence are overrepresented by ethnic minorities. Within the National Spinal Cord Injury Model System Database, 71.8 percent of those sustaining spinal cord injuries by violence have been ethnic minorities (NSCISC, 1994). Of those injured from 1980 through 1993 and rehabilitated for firearm associated spinal cord injuries within the Southern California Spinal Cord Injury Model System, 94.2 percent have been from ethnic minority groups, predominately Latino (54.1 percent) or African American (36.3 percent). Furthermore, of all Latinos and rehabilitated within the Southern California System during the same period, 49.2 percent have sustained their injuries by firearms. For African Americans, the data is even more alarming; of those treated within the system, 61.0 percent have sustained their injuries by firearms. In contrast, only 8.5 percent of all non-Latino white patients treated within the system had firearm associated spinal cord injury. Cases reported to the National Spinal Cord Injury Database since 1990 show similar trends, with 45.7 percent of spinal cord injuries among African Americans, 52.4 percent of injuries among Latinos, and 8.5 percent among non-Latino whites due to violence. In addition, the rise in violence from the perspective of the National Spinal Cord Injury Statistical Center is restricted to these two ethnic groups (Stover et al., 1995).

Firearm casualties are significantly younger than those injured by other causes (NSCISC, 1994; Stover et al., 1995; Young & Harris, 1982). While violence appears to result in spinal cord injury in all age groups, the Model

Spinal Cord Injury Systems reports that 21.1 percent of those under 15 years of age, 18.1 percent of those between 16 and 30, 17.5 percent of those between 31 and 45, 11.1 percent of those aged 46 to 60, 4.8 percent of those 61 to 75, and 2.7 percent of those over 76 have been injured as a result of violence.

In addition, while spinal cord injury happens to males predominately (82.2 percent), for injuries associated with violence the gender gap is somewhat larger. Of the 2,169 cases recorded in the local database of the Southern California System, 91.5 percent of those injured by violence are male.

Beyond the demographic data discussed above, published information on violence related spinal cord injury has been limited predominately to medical and surgical treatment with an emphasis on gunshot wound injuries; and the majority of this information is based on military experiences. Furthermore, because civilian gunshot wounds are caused primarily by low velocity handguns and military injuries by high velocity weapons that create more tissue damage, much of the available information is not applicable to civilian cases (Kane, Capen, Waters, Zigler, & Adkins, 1991).

We do have evidence that suggests that civilian spinal cord injuries due to gunshot wounds result more often in complete paraplegia rather than complete tetraplegia, or incomplete paraplegia (Kane et al., 1991; Waters, Adkins, Yakura, & Sie, 1991); that civilian spinal cord injuries due to gunshot wound, given current level initial antibiotic therapy provided, have lower

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incidence of wound infection than military experience suggests and warrant different treatment than suggested by military experience (Roffi, Waters, & Adkins, 1989); that removal of bullet fragments from the spinal canal in the thoracic region above the T12 level does not improve recovery or relieve pain but does in thoracolumbar region T12 and below (Waters & Adkins, 1991); and that neurologic recovery for gunshot wound spinal cord injuries within deficit categories (i.e., complete and incomplete paraplegia and tetraplegia) is no different than that for spinal cord injuries due to other causes (Waters, Sie, Adkins, & Yakura, 1995a). With regard to spinal cord injuries caused by violence other than those associated with firearms, the information is limited to injuries caused by stab wounds and it is minimal. These data indicate that stab wounds tend to result in more incomplete spinal cord lesions but, like gunshot wound injuries, neurologic recovery within deficit categories (i.e., complete and incomplete paraplegia and tetraplegia) is no different than that for spinal cord injuries due to other causes (Waters, Sie, Adkins, & Yakura, 1995b).

Despite the rising incidence of spinal cord injury resulting from violence, information concerning differences between individuals who have sustained their injuries by violence compared to other causes has been as restricted as that discussed above. There is virtually no published information on events that lead to spinal cord injuries caused by violence; characteristics of those injured other than age, ethnicity, and gender; or rehabilitation outcomes. The large proportion of ethnic minorities and youths injured by violence may influence outcome trends. In addition, violent etiology connotes that individuals injured by such means may possess certain attributes that might cause them to respond less successfully to rehabilitation than those injured by other means. Injury by violent etiology tends to conjure up first reaction visions of gangs and illegal or, at least, antisocial behavior. Indeed, among some it may be held that many of those injured by violence, versus other means, bear a

greater share of fault or guilt, or are somehow more accountable for their injury and, therefore, perhaps less deserving of the benefits of rehabilitation.

In a recent study, a group of individuals injured by violence was compared to a group injured by motor vehicle crashes. Since the focus of the study was firearm related injuries, we chose those injured in motor vehicle crashes for comparisons because motor vehicle crashes are the leading cause of spinal cord injury; and this is the only etiologic based group with a membership large enough and having adequately similar attributes to provide practical comparisons. We also restricted the sample to males and those who were injured between the ages of 18 and 35 to avoid the gender and age biases associated with violent injuries. Unfortunately, we could not avoid the ethnicity bias inherent in the population of those injured by violence. Of 164 individuals able and willing to provide relevant comparable data, none were non-Latino whites injured by firearms. In addition, nearly 90 percent of the African-American participants had been injured by firearms. However, among Latino participants the ratio was approximately 40 to 60 percent motor vehicle to firearm. We anticipate a portion of the results of this study will be available by the time this article is published (Waters & Adkins, in press). Among the findings which may be more relevant to rehabilitation were comparisons of the pre-injury characteristics: education and vocational training, employment, and indices of antisocial behavior.



Multiple gun shot wounds to the C4–C5 area of the spine.

Education and Vocational Training

When partitioned into the following categories (1) high school not completed, (2) high school only, and (3) more than high school education, the distributions of educational categories between firearm and motor vehicle injuries were not statistically different.

Ethnically, the distributions of educational categories were different than would be expected by chance. The primary difference was due to a higher percentage of Latinos—68 percent—with less than a high school education, which was more than twice the percentages of non-Latino whites or African Americans with less than a high school education. The percentages for non-Latino whites or African Americans were nearly equal. Interestingly, in this

sample, the African-American group had the highest percentage—26 percent—of individuals with education beyond the high school level, which was twice the percentage of non-Latino whites with education beyond high school and three times the percent of Latinos. Among Latinos only, those injured by motor vehicles had completed more years of education than those injured by firearms, but the difference was not statistically significant. Among African Americans in this sample, only five injuries were due to motor vehicles, and three of these five individuals had education beyond high school. Nevertheless, of the 12 African Americans with education beyond high school, 75 percent were injured by firearms.

Vocational or technical training as opposed to academic education was also assessed. The percentage of those with this type of training was nearly equal when partitioned by motor vehicle crash versus firearm, with 49 and 48 percent, respectively. Ethnically, the percentage of non-Latino whites and African Americans with vocational/technical training was equal: 61 percent for each group. For Latinos, the percentage was 36, a statistically significant difference from the other two ethnic groups.

Employment

Preinjury employment histories were different between etiologic groups. Ninety-nine percent of those injured in motor vehicle crashes had held a job sometime prior to their injuries versus 87 percent of those injured by firearms. Similarly, 94 percent of those injured in motor vehicles had been employed in the year prior to injury compared to 80 percent of those injured by firearms.

There were different preinjury employment histories for the different ethnic groups as well. However, the differences in employment histories did not coincide with the differences in education and vocational training as would be expected. Among the ethnic groups, 100 percent of the non-Latino white, 94 percent of the Latino, and 85 percent of African-American study par-

ticipants had held a job at some time prior to their injury. The data also indicate that 97 percent of non-Latino white participants, 89 percent of Latinos, and only 72 percent of African Americans in the sample had been employed at some time during the year prior to injury. Thus, while the Latinos had less educational experience and vocational training than the African Americans in this sample, a greater percentage had stronger employment histories.

Of all the differences discussed under antisocial behavior, ethnic and etiologic were the most statistically significant.

Antisocial Behavior

The self-reported arrest records of the participants indicated that nearly 20 percent more of those injured by firearms versus motor vehicles had been arrested at some time prior to injury. Ethnically, 26 percent more of the African Americans and 12 percent more of the Latinos had been arrested than the non-Latino white participants. Thus, 14 percent more of the African Americans than the Latinos had been arrested.

When asked if they had spent any time in jail, 25 percent more of those injured by firearms compared to those injured in motor vehicles responded affirmatively. Ethnically, 23 percent more of the African Americans and 10 percent more of the Latinos had spent time in jail than had the non-Latino white participants; thus, 13 percent more of the African Americans than the Latinos had spent time in jail.

With regard to gang activities prior to their injury, 26 percent of those injured by firearms indicated they had belonged to a gang sometime prior to their injury, and 16 percent were gang

members at the time of injury. In contrast, 12 percent of those injured in motor vehicles were gang members at sometime prior to injury and 5 percent at the time of injury.

Three percent of the non-Latino white participants indicated that they had belonged to a gang at some time prior to injury, versus 29 percent of the Latinos and 17 percent of the African Americans. None of the non-Latino white participants reported belonging to a gang at the time of injury, versus 16 percent of the Latinos and 11 percent of African Americans. Of all the differences discussed under antisocial behavior, ethnic and etiologic were the most statistically significant.

Outcomes

There were two primary outcome measures assessed in this study. The first was rehabilitation length of stay and the second was scoring on the *Functional Independence Measure* (FIM) (Keith, Granger, Hamilton, & Sherman, 1987). The FIM is currently perhaps the most widely used outcome measure in physical rehabilitation. It was designed to assess burden of care and was used in this study to provide a measure of disability and indicate degree of skill in activities of daily living at discharge from rehabilitation. The FIM assesses the following areas: self-care, sphincter control, transfers, locomotion, communication, and social cognition.

Surprisingly, despite the considerable differences in pre-injury factors discussed above between etiologic and ethnic groups, there were no significant differences in outcomes at the end of discharge. Those with firearm injuries had a lower average rehabilitation length of stay that bordered on statistical significance; however, the difference was accounted for by degree of neurological deficit and associated injuries. There were more individuals with tetraplegia in the motor vehicle group and more associated injuries in this group. In fact, injury severity measures accounted for virtually all of the explainable variance in outcome measures, and the pre-injury factors dis-

cussed added practically nothing to the predictive power of the model. Thus, whatever differences in ethnicity, education, training, employment, or indices of antisocial behavior individuals brought with them to rehabilitation, they did not measurably influence the medical rehabilitation process. The primary differences associated with etiology was severity of injury, which naturally influences rehabilitation outcome.

We have just begun to examine long-term outcomes (e.g., postrehabilitation employment, educational endeavors, handicap, preventable medical complications) in this study and as of the present have found only one major difference between groups. Those with firearm injuries have had nearly twice as many problems with postrehabilitation pressure ulcers as those with injuries resulting from motor vehicle crashes. However we have not yet determined what factors may contribute to this difference.

Prevention

Prevention of spinal cord injuries caused by violence is now becoming of increasing interest among those who treat victims of spinal cord injuries. Prevention measures for cancer, heart disease, and automobile trauma have been very beneficial. The fact that most health-care professionals come into contact with the person after the injury is sustained may be why prevention has not been a major rehabilitation issue. But the human and economic toll exacted by senseless interpersonal violence is now causing healthcare professionals to focus increasingly on prevention as part of their rehabilitation duties.

The public health model of prevention fits nicely into preventing spinal cord injuries. Identifying risk factors and attempting to intervene before the injury occurs is currently the only cure for a spinal cord injury.

However, there are very few programs that can specifically deal with the prevention of spinal cord injuries as a result of violence. Programs that are successful in reducing violence will hopefully reduce spinal cord injuries as a product of decreasing violence in general.

Peer based prevention programs are one example of a violence prevention program. Teens on Target is a program that utilizes persons who have sustained spinal cord injuries as a result of a violent act to speak to at-risk youths concerning the potential consequences of their risk taking behavior. Many young people believe that, if they are injured, they will either die or get better. Most teenagers do not think about the consequences of a lifetime of disability.

The Think First prevention program initially dealt with diving and, later, motor vehicle crashes. Now, the issue of violence as a cause of spinal cord injuries is also being addressed.


School and community based conflict resolution programs are another prevention tool. Many young people do not have the skills to resolve conflicts in a nonviolent manner. There are numerous programs that teach children conflict resolution and anger management and build self-esteem.

Alcohol use has been implicated in the cause of spinal cord injuries.

Alcohol use has been implicated in the cause of spinal cord injuries. Schandler (1995) found that the family history of alcoholism of persons with spinal cord injuries was over four times that found in the general population. Information concerning alcohol use and abuse should be part of any prevention program. In this regard, in our study discussed above 40 percent of those injured admitted to having been drinking alcohol within 2 hours prior to their injury, and there was no difference in this fact among those injured by firearms

versus those injured by motor vehicles. However, of those admitting to alcohol consumption, 72 percent of those in the motor vehicle group believed that alcohol consumption played a role in their injury compared to only 43 percent of those in the firearms group. In a related issue, only 7 percent of those injured in motor vehicle crashes admitted to using drugs prior to their injury, versus 21 percent of those injured by firearms. However, nearly 60 percent of both groups felt that the drug use contributed to their injuries.

In any epidemic, there is always a vector perpetuating the damage. In malaria, it was the mosquito; in bubonic plague, it was fleas carried by rats. In spinal cord injuries as a result of a violent act, it is the firearm, particularly the handgun. Reducing the availability of firearms coupled with education is absolutely critical in reducing injuries from firearms. Safety devices such as trigger locks, loaded chamber indicators, and childproof guns should also be implemented.

The results of prevention programs are difficult to document, and funding them has been problematic. A comprehensive effort to deal with the overall prevalence of violence in our society, to stress the negative effects of alcohol and substance abuse, and to reduce the availability of firearms is needed to mitigate the rise in spinal cord injuries from violence. It is essential that various disciplines take this matter to their professional societies and strongly encourage them to make prevention a priority. 

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In Memoriam

Joseph M. LaRocca



Mr. Joseph M. LaRocca, an international leader and noted pioneer in rehabilitation for over half a century, died September 27 at his Silver Spring, MD, home after suffering a stroke. He was buried with honors in Arlington National Cemetery. During World War II, Mr. LaRocca served with distinction as an officer in the U.S. Navy.

He was born on Nov. 23, 1908, in Cleveland, OH, graduated from Cornell University, and completed training at the Graduate School of Applied Social Sciences of Western Reserve University. He is survived by his wife of 58 years, Margaret Hunter LaRocca; a daughter, Margaret L. Bishow, of Takoma Park, MD; a son, Robert J., of Philadelphia; a brother, Charles, of

Cleveland; a sister, Mildred Wright, of Portland, OR; and two grandchildren.

Mr. LaRocca advised organizations and agencies, such as the International Rescue Committee, Urban Institute, World Rehabilitation Fund, and the State Department about setting up medical and vocational rehabilitation programs, largely in war-torn countries. He began his career in the 1930's with the Works Progress Administration. He directed sharecropper assistance programs in Atlanta, GA, and Jacksonville, FL, before moving to Washington in the late 1930's.

In Washington, he was an advisor to the Bureau of Public Assistance of the Social Security Administration, helping with the initial Social Security reg-

ulations, and later became a senior administrative officer with the Federal Security Agency.

After serving with the Navy in the Pacific during World War II, he returned to work at the Social Security Administration. He was a regional representative for vocation rehabilitation in New York and chief of guidance, training, and placement but also was assigned as a public welfare advisor in Greece and Egypt for the State Department.

Mr. LaRocca was technical director for rehabilitation in the White House Conference on Aging in 1959 and 1960 and executive secretary of the National Citizens Advisory Committee on Vocational Rehabilitation from 1965 to 1967.

In the rehabilitation field, Mr. LaRocca, or "Joe," as he was called by all of his friends, will always be remembered with honor and appreciation. He devoted many years to providing exemplary services that have contributed immeasurably to the quality of life for people with disabilities. He served in the original Vocational Rehabilitation Service (precursor to the Office of Vocational Rehabilitation, OVR, later known as the Vocational Rehabilitation Administration, VRA, and currently designated the Rehabilitation Services Administration, RSA). His service to the federal rehabilitation program extended from 1943 to 1965. During this period, he served as special assistant to Commissioner Michael Shortly and to Commissioner Mary E. Switzer and as Director of the International Program. He was responsible for legislation, for the development of standards to insure the quality of state operations in the national program of rehabilitation, and for the management and direction of the international program.

The 1965 Amendments to the Rehabilitation Act provided for a major expansion of the national program, which included basic services, research and demonstration, training of professional personnel, and new federal initiatives for the hearing and visually impaired and others with severe disabilities. Commissioner Switzer appointed Mr. LaRocca chairman of a task force to develop regulations for implementation of

these far-reaching provisions. He consulted with experts on a daily basis and obtained the recommendations of specialists in every field of endeavor. Decisions were made and new national policies adopted to insure a major expansion in the development and implementation of programs. These provisions have improved the quality of life each year for more than 200,000 people with disabilities over a sustained period from 1965 to date. If one person can be singled out as critical to their implementation, that person was Joseph LaRocca.

Mr. LaRocca subsequently served as administrator of the George Washington University Research and Training Center in Washington, DC, and as the primary consultant to the Urban Institute in completing the statutorily mandated *Comprehensive Needs Study*. The findings from this study led to legislative amendments that authorized the current national program of rehabilitation for all Americans with physical and other disabilities.

At the same time, Mr. LaRocca was also providing leadership in the development and implementation of Public Law 480 for the support and encouragement of rehabilitation programs in developing and war-torn countries. His work led to efforts in Cyprus that

brought Turkish and Greek Cypriot doctors together and to a similar program uniting physicians in war-torn Lebanon. He advised medical practitioners in Laos and Vietnam treating farmers injured by land mines and helped plan training for healthcare workers in India, Bangladesh, Israel, Mozambique, and Uganda.

In Mozambique, a country with an estimated 20,000 amputees caused by over a decade of devastating civil war, Mr. LaRocca led the rehabilitation effort personally. Drawing upon a wealth of knowledge about the issues and his consummate diplomatic skills, he rallied the cooperation of several private voluntary and international agencies, the Mozambique government, and the U.S. embassy in support of a war victims project. Our embassy had never participated in any project like this before. In both Mozambique and Uganda, he produced timely reports on needs and recommendations that were incorporated virtually verbatim into those countries' war victim plans.

In cooperation with the Agency for International Development, Mr. LaRocca handled numerous difficult assignments in the Middle East, Asia, Africa, and South America. He was always ready to give his time without consideration of payment, to jump on

an airplane for distant and dangerous parts of the world, and to go the extra mile to make certain that a program not only worked but worked well. Recently, the staff of the United States Senate responsible for these programs shared with me their appreciation and their regard for Joe as "a national treasure."

He was also a very caring and humble individual, always interested in getting the job done and serving the scores of people in need of services, rather than seeking the limelight. In his work overseas, he was always viewed as an ambassador of goodwill and hope. He saw rehabilitation as an international language that served as a bridge between peoples to enhance mutual trust and respect and, especially, peace between nations. His commitment and dedication were matched only by his foresight and selfless resolve to help people gain independence and dignity.

This past year, in celebrating the 75th anniversary of the Rehabilitation Act at a reception during the Switzer Memorial Seminar, Joe LaRocca was selected as an honorary Switzer Scholar for his work with other legends in the field of rehabilitation, including Mary Switzer, Howard Rusk, M.D., and James Garrett, Ph.D. In 1990, Dr. Garrett told me that Joe had spent a lifetime dedicated to meeting the needs of people with disabilities and "that those who would honor Joe would, in reality, be honoring themselves."

In summary, Joseph M. LaRocca helped shape the history of rehabilitation. He made an immeasurable contribution to the quality of life for people with disabilities and served as a role model for others. Through his wonderful family, his many friends, and his inspiration to all of us, Joe LaRocca will always be remembered and his work will be of lasting benefit to world rehabilitation.

Wesley E. Geigel

Director, Federal Program Liaison
Electronic Industries Foundation.
Former Director of the Division of
Rehabilitation Facilities, Deputy
Assistant Commissioner, and Acting
Assistant Commissioner, Office of
Developmental Programs, RSA.



"The yearnings for usefulness, for the warmth of family and friends, and for the respect of the community are very real factors in rehabilitation, for upon these are built the services that give substance to hopes and desires."

— Joseph LaRocca,
from *Rehabilitation for the Aging:
A Growing Responsibility*

"The outstanding thing that rehabilitation achieves is preservation or the restoration of dignity to the individual. We in the rehabilitation field are fortunate to have so precious an objective and purpose which in reality gives meaning to life."

— Joseph LaRocca
(Excerpt from paper prepared for the
Seventh Annual Institute for Rehabilitation
Personnel, Southern Illinois University).

Quality of Life After Spinal Cord Injury

Marcel Dijkers Ph.D.

"Quality of Life is a vague and ethereal entity, something that many people talk about, but which nobody very clearly knows what to do about"

(Campbell, Converse, & Rodgers, 1976).

The term, *quality of life* (QOL), was first introduced in the 1950's as a political slogan. Initially, the idea of the good life referred only to entire populations (as in "the quality of American life"), but in the seventies a gradual shift occurred and the term was applied to individuals. Since then, it has become a notion bandied around by politicians, human service providers, policymakers, journalists, and especially academicians, who have worked tirelessly to define and measure the goodness of life of societies, groups, and individuals.

Three traditions of research have emerged (cf. Dijkers, in print). The first—social indicators research conducted by economists, geographers, and others—focuses on what can be termed "basic preconditions of quality of life in a community," such as percentage of homes with running water, economic growth, political stability, etc.

Social indicators research deals with QOL at the level of a society or other geographic or political entity.

The second approach, of economists, sociologists, and other social scientists, investigates, at the level of the individual, the acquisition and loss of "the good things in life," such as education, income, material possessions, health, and community functioning. Healthcare researchers have realized that biological markers of disease activity, or even mortality and morbidity, are not always the most relevant indicators of successful interventions. This has resulted in an increased focus on measuring outcomes that are of direct interest to patients, such as health status, function, pain, and components of psychological well-being.

In a third shift, sociologists, social psychologists, and gerontologists moved from objective individual-level QOL to reported subjective quality of individual lives. They investigate people's cognitive (satisfaction) and affective/emotional (happiness) reactions to specific domains of their life, such as career, marriage, and health, and their opinions and feelings about their life as a whole.

Quality of Life, People with Disability, and Rehabilitation

The recent and large increase in the number of people with chronic diseases and injury sequelae, such as stroke, arthritis, and spinal cord and brain injuries, is the reason behind the emer-



Photo by Blake J. Discher Photography

gence of quality of life as a major concern in the healthcare field. Although there is no cure for those disorders, pain and discomfort can be relieved, function enhanced, adjustment supported, and mental health improved. Nonmedical rehabilitation specialists, including vocational counselors and human service providers, have an interest in the same QOL outcomes, although they accomplish them through other types of interventions.

Fuhrer (1994) noted that there is a lack of studies using subjective well-being to measure the result of specific rehabilitation interventions and that there is almost no knowledge of how more traditional outcome measures (activities of daily living, independence, decreased complications, etc.) relate to subjective well-being.

On average, people with disabilities have a lower quality of life than nondisabled people, if objective measures are considered. They have impairments that almost always impose activity restrictions, and frequently impact cognitive and affective functioning. They have a major chronic illness with various signs, symptoms, and, sometimes, treatment side effects. If healthy, they often have a razor-thin margin of health, and frequently struggle with various acute illnesses. Activity restrictions and other forced lifestyle modifications often lead to secondary disabilities, such as pressure sores and carpal tunnel syndrome.

Health and disability-related problems are not the only ones, however. People with disabilities rank lower than their nondisabled counterparts in almost all measures of QOL that are not (or not directly) related to health (Thompson-Hoffman and Storck, 1991). Impairments and disabilities rob them of educational, vocational, and other opportunities, or at least severely restrict chances to enjoy such things as community participation, contact with others, parenting, and sexual intimacy. Census and other statistics show that people with disabilities have less education, more often are unemployed, and have lower incomes.

However, these differences with the nondisabled population in terms of objective QOL do not mean that people with disabilities have a lower subjective QOL. They are not by definition less happy, less satisfied with life, and less able to live productive lives. Impairment and disability can be very minor influences on one's judgment of overall life quality, and persons with disabilities may derive satisfaction from the same things as do nondisabled persons (material well-being, a successful marriage, etc.) to the same degree. Their overall level of life satisfaction is not necessarily lower than that of their nondisabled peers. This does not mean that the subjective, self-assessed QOL of persons with disabilities is *never* affected by their impairment or disability. Some obviously report diminished QOL compared to nondisabled peers or compared to themselves prior to the onset of disability.

Spinal Cord injury: Objective Quality of Life

In its consequences, a spinal cord injury (SCI) is like a stone thrown in a pond: increasingly wider areas of the life of the persons involved, and those around them, are affected. The impairment that is immediately obvious (sensory and motor deficits) may result in a limitation of or even total loss of the ability to perform common tasks such as self-care and walking. These abilities, in turn, commonly result in restrictions of role fulfillment as a worker, student, parent, citizen, and so forth. Sometimes these disadvantages are due not so much to disability as to societal reactions: negative attitudes and discrimination toward people with disabilities, which may be triggered by the mere fact of impairment. The person with spinal cord injury has to cope not just with a changed body image, new ways of doing things, and increased reliance on others for the performance of common tasks but also with changes in his or her social roles and interactions.

A recent publication (Stover, DeLisi, & Whiteneck, 1995), reporting results of more than 20 years of data from the

SCI Model Systems, provides a summary of the most important objective QOL measures, including mortality, morbidity, secondary disabilities, and functional outcomes. The following section (from the heading, "Residence," to "Marital Status") is summarized from the chapter on social outcomes (Dijkers, Buda Abela, Gans, & Gordon, 1995).

Residence

The data in the National SCI Model Systems Data Base show that upon completing initial rehabilitation, the vast majority of persons with spinal cord injury (92.3 percent) are discharged to a private residence in the community. Very small numbers go to hospitals (1.4 percent), or nursing homes (4.0 percent). Some go to group living facilities (e.g. correctional institutions), usually for reasons other than medical or personal care needs (1.9 percent).

Institutionalization is a crucial QOL outcome, as it almost always imposes restrictions over and above those due to the impairment and disability itself, including: restricted access to community settings; limitation on the number and variety of social interactions (including with potential romantic/sexual partners); impoverishment of the number and/or quality of social roles played; and decreased self-determination, independence, and privacy. Institutional residence is the antithesis of independent living, and is considered an outcome indicating poor QOL.

Changes in economic, medical, and social circumstances in the years following discharge may result in changes in residence. On the whole, the percentage of persons residing in nursing homes and hospitals declines over the years after injury, and the percentage living in a private residence or other community setting increases. A rough estimate is that at any time, 2.6 percent

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of all persons with spinal cord injury live in a medical setting.

Employment

Return to work is often used as an indicator of overall recovery from illness or injury. At one time, employment was even equated with rehabilitation success. SCI reemployment figures reported in the literature vary tremendously (within a range from 13 to 48 percent) in terms of when the study was done, sample composition in terms of age, time since injury, neurological category, and by definition of employment. There is also much variation in the factors reported to be associated with employment, both preinjury (education, employment) and postinjury (neurological category, receipt of vocational rehabilitation services, etc.). However, a few generalizations may be made, based upon more recent studies, all of which were confirmed in the analysis of the National SCI Data Base information:

- Paraplegics have higher employment and reemployment rates than tetraplegics; and within both disability categories those with incomplete injuries are more likely to be employed.
- Those who incur spinal cord injury at a younger age are more likely to become (re)employed.
- Employment rates increase with years after injury.
- The less education preinjury, the less likely employment.
- Preinjury vocational experience predicts postinjury employment.
- Blacks and other minorities are less likely to become (re)employed, even taking into account age, education, gender, marital status, and neurological category.
- Completion of a vocational rehabilitation program makes employment more likely.

National Data Base information indicates that whereas over 60 percent of persons with spinal cord injury were working preinjury, at 1 year postinjury the most frequently reported status is unemployed (61.9 percent). By the first

anniversary of injury, only 16.1 percent of those working at the time of injury have returned to work. About 8 percent of them have entered school and more than 70 percent consider themselves unemployed. In contrast, almost half of those who were homemakers at the time of injury have revived that role (49.1 percent), and almost 71 percent of those who were students have resumed their education.

Changes in vocational status appear to be most common in the earlier years after injury, with the exception of leaving the student status. The net result is an employment rate that increases steadily to reach a peak of 30 percent at about 10 years after injury.

Education

Of all cases entered into the National Data Base, at the time of their latest followup, 15.1 percent had improved their education level from the time of injury. As expected, the change is most pronounced for those under 17 at the time of injury (49.3 percent). Of those who were 17 through 25 years old at injury, 19.3 percent have improved their grade level, as have 6.2 percent of those who were at least 26 at the time they incurred their spinal cord injury. Data indicate

that those who are white increase their grade level more frequently than those of other races. Except in the 26+ age group, tetraplegics achieve an advanced education more often than do paraplegics, and those with complete injuries do so more often than those with incomplete injuries. This presumably reflects their need to obtain a higher level of education, rather than ability or other factors. The data suggest that for persons with spinal cord injury, the educational process is delayed and extended. The educational level of those for whom 15th anniversary of injury information is available is better than that of the U.S. population as a whole.

Marital Status

Given the young age at which spinal cord injury typically occurs, it is not surprising that the majority of cases in the National Data Base (54.2 percent) were single at the time of rehabilitation discharge. In addition, 30.1 percent were married, 9.0 percent divorced, 4.4 percent separated, and 2.1 percent widowed.

During the first 6 years, from 1 year to the next, on average 2–2.5 percent of those who were single (never married) become married. From 10–30 per-



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cent of all those in a not married category at injury have married by the 15th anniversary. Of those who are married, in any year a small percentage gets separated or divorced. The separation rate declines from 4.2 percent in the first year after injury to close to 0 percent in year 15. The divorce rate varies between 2.0 and 3.1 percent in years 1 through 8, and thereafter quickly declines to almost 0 percent.

All rates of change in marital status tend to be highest in the early years after injury, indicating that both the disturbances of marital relationships and the reduced opportunities to get married which SCI brings about decline in importance over the years. The net result is that the total percentage divorced increases over the years, as does the percentage married. The percentage who are single (never married) declines correspondingly, while the separated, widowed, and "other" groups stay about the same size. Comparisons with age and sex specific U.S. marriage rates indicate that persons with spinal cord injury are less likely to get married in the first 5 years after injury (11.5 percent vs. 34.5 percent); similarly, comparison with age and sex specific divorce rates indicates that they are more likely to get divorced during the first 5 years after injury (17.4 percent vs. 11.3 percent).

Spinal Cord Injury: Subjective Quality of Life

Extensive literature exists on the psychological and emotional sequelae of spinal cord injury, studied under such labels as coping and adjustment, depression, disability acceptance, and control (an overview may be found in Trieschmann, 1988). Studies that require persons with spinal cord injury to report their QOL globally or their satisfaction with various domains of life have, however, become common only during the last 10 years. The first one (Crewe, 1980) found that SCI subjects reported less life satisfaction than nondisabled persons, especially in the domains of sexual relations with spouse, employment, and financial (material) well-being, but also in the

	N of Cases	Mean Corr.	95 % Confidence Interval	
			Low	High
Impairment	847	-.05	-.12	.02
Disability	829	-.21	-.27	-.14
Mobility	252	-.31	-.42	-.19
Family role	264	-.17	-.28	-.05
Occupation	843	-.30	-.36	-.24
Formal soc. integr.	300	-.41	-.50	-.31
Informal soc. integr.	696	-.28	-.35	-.21
Social support	750	-.49	-.54	-.43
Handicap— all components	3,279	-.34	-.37	-.31

spheres of health and social relationships. Many other authors have found a low subjective QOL for persons with spinal cord injury, compared to a matched group or compared to the population at large (see Dijkers, 1996).

There is less consensus with respect to other findings. In a recent review, Fuhrer (1996) summarized findings by 19 studies (mostly published since 1990) of the relationship between subjective well-being (satisfaction, morale, happiness, etc.) and the three components of disablement: impairment, disability, and handicap. Many "no relationship" findings were reported, in addition to the expected ones (low QOL is associated with high impairment, disability, or handicap). It is possible that in the latter studies the lack of a statistically significant relationship was due to small sample sizes resulting in lack of statistical power. The discrepant findings may also be due to other methodological weaknesses, the varying nature of the samples employed in the studies (in terms of age, time since injury, gender, etc.), or the range of instruments used to measure subjective QOL. Fuhrer (1996) was limited to concluding that QOL appears to be little, if at all, related to impairment, inconsis-

tently to disability, and commonly to various aspects of handicap. The relative strength of the relationships, or the circumstances under which disability affects QOL, could not be addressed in his qualitative review.

Dijkers (1996) extended Fuhrer's study by means of a meta analysis of 16 samples reported in 27 publications. Meta analysis is a method of statistically combining the results of multiple studies, with special attention to the consistency of effect sizes—the *strength* of the relationship between two variables, rather than statistical significance. I found an average correlation of $-.05$ (not significant) between *impairment* (level and/or completeness of the spinal injury) and subjective QOL, indicating that impairment by itself has no or a very minor effect on well-being (see Table 1). The association between disability and QOL was generally reported to be negative (the higher the disability level, the lower the QOL reported), and weak to moderately strong: the average over seven studies was -0.21 .

Several aspects of handicap can be distinguished, making it possible to analyze the association between QOL and various handicap dimensions. Lack of a family role (spousal or parental) seems

Table 2
Association of QOL with time factors.

	N of Cases	Mean Corr.	95 % Confidence Interval	
			Low	High
Current age	947	-.05	-.11	.01
Age at injury	584	-.05	-.13	.03
Time since injury	436	.09	.00	.18

to result in a lower QOL (average correlation of $-.17$). Occupation (work, attending school, or other productive activity) is an even stronger determinant, according to the consensus of 10 reports. The mean correlation is $-.30$. Results for the effects of mobility suggest that it is a fairly strong correlate, with a mean value of -0.31 , indicating that those with a mobility handicap have a lower QOL. Social integration, into formal social organizations or into informal networks of friends and acquaintances, is also a fairly strong determinant: the mean correlation was -0.45 for formal social integration, $-.29$ for informal.

Meta analysis cannot answer the question: what is cause and what is effect? While there can be little doubt that impairment level is the determinant of QOL (if a relationship exists), it certainly is possible for subjective well-being to affect disability and handicap. Someone who for whatever reason does feel that his or her life is not the best it could be is not likely to engage in self-care activities that constitute an effort, let alone spend energy in taking up or discharging the various social roles that are common for people of the same age and sex. Without longitudinal research that makes it possible to statistically sort out the reciprocal effects of QOL and handicap, it is difficult to estimate to what degree well-being affects handicap and disability.

Because subjective quality of life is such a new area of study, the literature is lacking in hypotheses as to what specific elements of the "cascade of conse-

quences of injury" have the most effect on well-being. We have limited information on what are the determinants of subjective QOL for persons with spinal cord injury, overall, in various subgroups, and over time. The findings reported here may come as a surprise to some (e.g., that the paralysis itself plays no larger role). For others, they may confirm that integration into family, the work force, and the larger community is the most crucial element. In a sense, the ranking of the three disablement components in terms of their correlation with subjective QOL is good news. While there is little that can be done to decrease impairment, especially in chronic SCI patients, rehabilitation specialists have the skills to diminish disability by furnishing training, providing aids and appliances, and so forth. They also can do much to minimize handicap, although changes in the larger society often are also needed, such as breaking down attitudinal barriers and undoing financial disincentives.

Recently, concern has been expressed that aging with a spinal cord injury will result in a range of medical, functional, and psychological problems that were not encountered when survival after such an injury was limited. A few authors have addressed the double burden of aging and disability (e.g., Trieschmann, 1987; Menter, 1994), often guided by the assumption that people who live with a spinal injury age faster. Because of this, the effects of age at injury and time since injury on QOL are of interest. Time since injury also is im-

portant from another, short-term perspective: most people, when asked to rate what subjective well-being they would have if they were to incur a spinal injury, come up with scores much lower than people with a spinal cord injury themselves do, on average. We can assume that immediately after injury, persons who incur a spinal cord injury have the same opinions and feelings. Part of "adjustment" must include changing this image of oneself and one's QOL.

A second meta analysis I did (Dijkers, unpublished) focused on time trends in QOL in persons with spinal cord injury (see Table 2). The reported correlations between QOL and time since injury were, with one exception, not significant. However, they all were positive, and the average correlation (weighted for sample size) was 0.09 . This suggests that persons with a longer time since injury tend to rate their subjective well-being higher.

Four studies reported five correlations with age at injury. Except for one, all were positive, indicating that those injured at a younger age experience a better QOL. The average correlation was calculated at -0.05 . The correlations reported between current age (that is, at the time of study) and QOL generally were negative. The average was also calculated at -0.05 : persons who are older report lower QOL. (Both correlations are not statistically different from 0.00 —no relationship.)

If the effects of time since injury and current age both are linear, they cannot be distinguished from one another: a person who puts 10 years' distance between herself and the injury ages 10 years at the same time. Any effect of "aging" may be attributed to "adjustment," and vice versa. The fact that contradictory correlations were found (although not necessarily statistically different from one another) suggests that two different processes may be at work. "Adjustment" may be a short-term process resulting in a fairly sharp increase in self-rated QOL. Experts disagree on how long it takes, but anywhere from 2 to 7 years is suggested. "Aging" quite likely is a much slower process taking place over many years,

resulting in a gradual decline in QOL. Most general population studies have found a slow decline in QOL with increasing age, at least for males, and most persons with spinal cord injury are male.

It must be noted that, with one exception, the studies included in this second meta analysis were cross sectional rather than longitudinal. Cross sectional studies have a number of disadvantages in studying change, including selective attrition and inability to distinguish aging effects from the consequences of changes in the world at large. More research in this area is needed, utilizing longitudinal designs incorporating multiple cohorts.

Conclusion

A spinal cord injury is no longer the almost certain threat to life it once was, before the invention of antibiotics and the development of medical technology. It also is not the catastrophe many still consider it to be. The majority of persons survive the spinal injury and go back to living. Due in no small measure to the interventions of medical, social, and vocational rehabilitation, many are successful. The vast majority lives in the community, not in an institution. Most of those who were in school at the time of injury go back, and some of those who had completed schooling or dropped out return, with the end result that persons with a spinal injury tend to be as well-educated, if not better educated, than the population as a whole. However, in spite of educational efforts, work is still an elusive goal for many. The various consequences of spinal cord injury do have an effect on family life and a person's chances of becoming married; compared with their peers, persons with a spinal injury are more likely to become divorced and less likely to get married.

These various restrictions in social roles, added to health problems and issues of psychological adjustment to a changed body, together constitute formidable challenges. Most people without spinal cord injury think that life with such a serious injury would not be



Quotes from persons with spinal cord injury interviewed as part of the author's ongoing study of quality of life after spinal cord injury.

"So, the company offered me to [come back] to work on the [shop] floor for a little while and start. I was tickled. I come rolling out of the parking lot and I was crying. I told my wife: 'I got my job back!'"

"There's times I feel like I'm not a full man. I want to go out and shovel the sidewalk or do something to help [my family] out. Then, again, you just look at the chair. You're always going to need help for the rest of your life."

"Like they said: 'You're supposed to see that light at the end of the tunnel.' But that tunnel goes a long way before you see that light."

"I always thought that if ever I had an accident and I became a quad, I'd rather die. And yet, I met a number of people [with SCI] in the hospital and outside the hospital who seemed very happy—just for being alive and with their abilities. So, I guess, quality of life is: Are you happy with what you can do?"

"You know, I found out one thing: that it does not take a very big hunk of the good to balance out an awful lot of the bad."

"Well, whenever I got to complaining, when I hurt so bad, didn't do nothing, felt like I had to sit in the house, felt sorry for myself, didn't care about anybody else's feelings, I thought life was terrible. I thought this ain't life. This is existing."

"But I just want to make my family happy. When I'm down a day it affects them because it seems like I'm giving up. You know, it's like you want to tell them what's going on but you have no way of explaining my side of the view: 'You're not the one laying in this bed. You're not the one that got the sores. You're not the one.'"

"And quality of life—as an injured person—I think you'll change your definition [of quality of life]. Change completely because your quality of life goes from, I'd say, from day to night. I still have good quality of life, but I look to patients that I go to therapy with and I notice they are very sad. They don't want to work on their therapy. I find out, the families are not as helpful to them."

"I think [quality of life] has to be a relationship between what a person believes they are able to accomplish and believes they want to do and what is actually happening to them. If you have very low expectations then your quality of life may be easily met, and vice versa, obviously."

worth living. However, once someone incurs a spinal cord injury, that opinion is almost certain to change, sooner or later. While the suicide rate for persons with spinal cord injury is much higher than for the population at large, only a fraction take that step—usually during the early years. A series of studies have indicated that, after a stormy initial 2–5 years, most persons learn how to cope.

While the average person with a spinal cord injury still rates her or his subjective well-being lower than peers do, the difference is relatively small. It would seem that the impairment itself is hardly a concern, at least in the long term. It is the disability and, even more so, the handicaps that follow in its wake that seem to impact life satisfaction and morale. In the short term, QOL improves after injury; in longer term, there would appear to be a gradual decline. Further study is needed to determine whether that decline is sharper than in the population at large. **AR**

Acknowledgments

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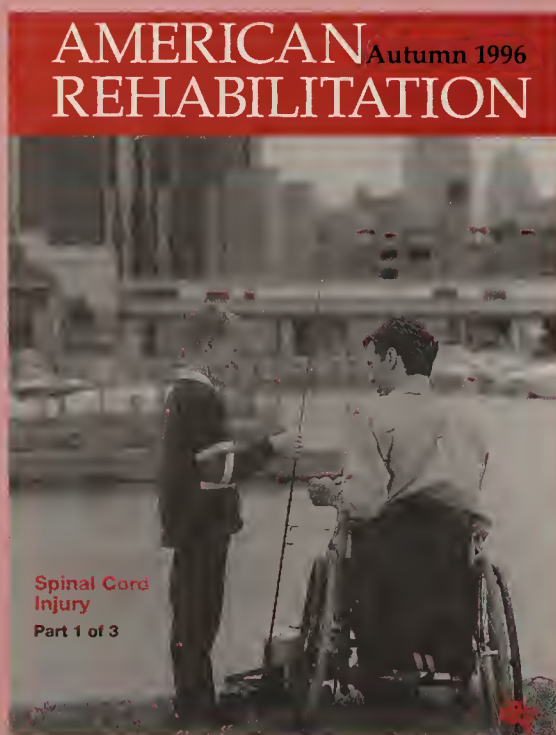
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Facts, Figures, and Trends on Spinal Cord Injury



Samuel L. Stover, M.D.

The Model Spinal Cord Injury Care Systems began as a concept in the Rehabilitation Services Administration (RSA). In 1968, several physicians in the speciality of Physical Medicine and Rehabilitation convinced Congress about the needs of spinal cord injury (SCI) victims and the disarray of service delivery for persons with spinal cord injury. Congress subsequently mandated that RSA (then located in the U.S. Department of Health, Education, and Welfare) review the service delivery for persons with spinal cord injury and report back to Congress. James F. Garrett, Ph.D., J. Paul Thomas, John S. Young, M.D., and others conceptualized a model systems approach. In 1969, RSA responded to Congress with a proposal for a program of research and demonstration projects to design, develop, and implement an organized continuum of care for spinal cord injury. The proposed model included:

- rapid case finding and referral,
- early rehabilitation coordinated by a highly experienced team,

- mechanisms for identifying and using all of the necessary community agencies and services to facilitate rehabilitation, and

- an aggressive long-term community followup program to ensure that gains achieved during rehabilitation were maintained.¹

In 1970, the first federally designated model SCI system was funded in Phoenix, Arizona, known as the Southwest Regional System for Spinal Injury, under the leadership of Dr. John S. Young. This demonstration Model System was to provide a comprehensive service delivery system within a defined catchment area and was to include 5 components:

- development of an effective emergency medical services system;
- acute care;
- physical rehabilitation;
- psychosocial and vocational services; and
- a followup program.

The demonstration project also included objectives to develop a database and maintain sufficient records to document the efficiency of this comprehensive system approach in the

management of persons with spinal cord injury, including rehabilitation outcomes and cost effectiveness.

In 1972, additional model systems were established and, over the past years, as many as 13 to 19 model systems have been designated and received funding, most recently through the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education.

Since 1975, each of the model systems has been required to participate in a data collection process, and RSA established the National Spinal Cord Injury Data Research Center in Phoenix, Arizona, as a central facility to collect and analyze data reported by the model systems. Since 1983, this activity has been located at the University of Alabama at Birmingham at what is now known as the National Spinal Cord Injury Statistical Center.

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Data has been collected using a common syllabus including definitions of the variables, uniform data collection forms, and instructions for collecting the data. Computerized discrepancy programs were developed to monitor the quality of the data submitted. Considerable efforts have been made over the years to maintain data accuracy, reliability, and continuity. Many of the demographic variables have remained unchanged since data collection was started. Other clinical, psychosocial, vocational, and followup variables have been changed to assure reliability and validity of the data collected and address new or additional research questions that are relevant to changes in delivery of medical services and changing healthcare policies.

The SCI database actually includes data since 1973, because seven of the model systems had already started collecting data using a common syllabus as early as 1973. The data were entered into the National SCI Database when the National Spinal Cord Injury Data Research Center was established in 1975.

Data have been collected using two separate instruments referred to as *Form I* and *Form II*. *Form I* was completed at

the time of initial hospital discharge and included epidemiologic and demographic data along with descriptive information describing events relating to the initial hospitalization(s) occurring prior to definitive discharge. *Form II* was completed on the anniversary date of the injury and included events occurring from discharge to the anniversary date. *Form II*'s are then also collected annually on the anniversary date of injury and cover the events of the year reported. From 1973 to September 1995, initial hospitalization records (*Form I*) are available on 16,799 individuals who sustained traumatic spinal cord injuries and 81,465 followup records (*Form II*) are available.

Some of the data in this report has been taken from the book, *Spinal Cord Injury: Clinical Outcomes from the Model Systems*, published by Aspen Publications, Inc., in 1995.² The chapters of this book were authored by persons from the model systems and included a major effort to analyze the data in the database from 1973 to 1992. Accurate analysis of these longitudinal data requires an intimate knowledge of the revisions of the database over the years as well as the reliability of each variable. When available, more recent information is

also provided, and efforts are made to show trends in SCI demographics and care that are occurring as a part of the natural history of spinal cord injury as well as the changing times in society and healthcare policy. For many of the demographic variables, the entire database is used. For other sections of the report, subsets of patients are used because of the time data collection was initiated for those variables or to make sure that the data collected were the most accurate available.

Incidence and Prevalence

Only persons treated at model systems are included in the SCI database; therefore, the database was not designed to determine either the incidence or prevalence of spinal cord injury. It has been extremely difficult for anyone to obtain incidence and prevalence statistics using population-based studies. Most studies are derived from state registries or hospitalization figures.³ Trends over time are still uncertain. It is generally accepted that the incidence ranges from 30–45 cases annually per million population. The higher figures usually include deaths prior to arrival at the hospital.

Studies of prevalence have ranged between 525 and 906 persons per million population, with 721 to 906 considered to be the most likely range.³ Applying these prevalence estimates, it would suggest there were 183,000 to 230,000 people with spinal cord injury in the United States in 1992.⁴

Age at Injury

Spinal cord injury occurs most frequently in teenagers and young adults. The most common age at injury is 19, with 32.8 percent of all injuries occurring between the ages of 17 and 23. Almost 80 percent of injuries occur between the ages of 16 to 45³ (see Figure 1). The average (mean) age of injury is 30.7 years, with a median age at injury of 26 years. The mean age of injury is only slightly higher for females—32.2 years—than for males—30.3 years. There has been an increase of 4.9 years in the mean age at

Figure 1

Age of persons at time of spinal cord injury (n=16,796)

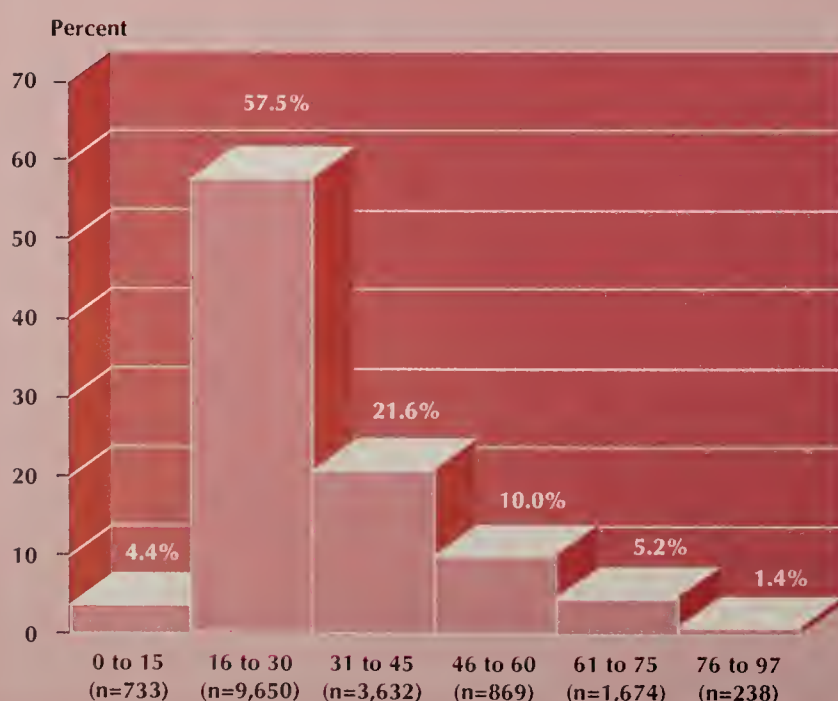


Table 1
The 18 Model Spinal Cord Injury Care Systems

- University of Alabama at Birmingham
- Regional SCI Care System of Southern California, Downey
- Northern California SCI System, San Jose
- Rocky Mountain Regional SCI System, Englewood, CO
- Georgia Regional SCI System, Atlanta
- Midwest Regional SCI Care System, Chicago
- Boston University Medical Center Hospital
- University of Michigan Model SCI System, Ann Arbor
- Southeast Michigan Regional SCI System, Detroit
- University of Missouri, Columbia
- Northern New Jersey SCI System, West Orange
- Mt. Sinai SCI Model System, New York
- MetroHealth Medical Center, Cleveland, OH
- Regional SCI System of Delaware Valley, Philadelphia
- Texas Regional SCI System, Houston
- Medical College of Virginia, Richmond
- Northwest Regional SCI System, Seattle
- Medical College of Wisconsin, Milwaukee

time of injury since 1973. Those who were at least 61 years of age at the time of injury increased from 4.5 percent for the period 1973-1977 to 8.5 percent since 1990.³ These trends are not surprising, because the median age of the general population in the United States has also increased from 27.9 years in 1970 to 33.1 years in 1991.⁵

Gender

A four-to-one male-to-female ratio has varied little throughout the history of the model systems data collection. Overall, 82.2 percent of all persons are male with only a slight decrease to 80.8 percent during more recent years.³

Racial/Ethnic Groups

Trends over time show significant changes in the racial distribution of persons admitted into the model systems. From 1973 through 1977, 76.9 percent of persons enrolled in the National SCI Database were white, 14.0 percent were African-American, 6.2 percent Hispanic, 2.1 percent American Indians, and 0.8 percent Asians.³ More re-

cently, from 1990 to 1992 only 56.3 percent of persons were white, 29.9 percent were African-American, 11.2 percent Hispanic, 1.6 percent Asian, and 0.4 percent American Indians. These general trends have been consistent during each successive year since 1973. Although white persons in the U.S. general population decreased from 83.1 percent to 80.3 percent between 1980 and 1990, the proportion of African-Americans increased slightly from 11.7 percent to 12.1 percent, and those of Hispanic origin increased from 6.4 percent to 9.0 percent. The U.S. racial trends are insufficient to account for the observed trends in the SCI population.⁴ The changes in these injury trends

are most likely a result of changes in the trends of etiology of spinal cord injury.

Etiology

Although motor vehicular crashes remain the leading cause of spinal cord injury, there are interesting trends in the SCI database showing the proportion of injuries due to motor vehicular crashes and sporting activities are declining while the proportion of injuries from acts of violence have increased steadily since 1973 (see Table 2). Prior to 1979, motor vehicular crashes caused 46.9 percent of spinal cord injuries, whereas from 1991 to 1994 they caused only 35.9 percent. Sports injuries have decreased from 14.4 percent to 7.4 percent during this same time period. On the other hand, acts of violence have more than doubled, increasing from 13.2 percent to 29.8 percent. The trend of increased acts of violence has been limited to minorities, including the African-American and Hispanic populations. In certain geographic urban areas, acts of violence are now the leading cause of spinal cord injury. These figures suggest that vehicular crashes may not actually be decreasing in total numbers, but are only decreased proportionately to other causes which have markedly increased.

The etiology of spinal cord injury also varies considerably by age and gender. Vehicular crashes are the leading cause of spinal cord injury up to the age of 45; however, after age 45 falls become the leading cause with a steady decline due to sports activities and acts of violence. In general, females are injured less frequently with sports related accidents and acts of violence but have a greater proportion of injuries from motor vehicle crashes.

Table 2
Trends in etiology of spinal cord injury

	Automobile Crashes	Sports	Falls	Acts of Violence
Prior to 1979	46.9%	14.4%	16.5%	13.2%
1991-1994	35.9%	7.4%	20.0%	29.8%



Preston Scarber, using computer.

Neurologic Level of Injury

Figure 2 shows the neurologic levels of injury at discharge from the model systems. The most common neurologic injury level is C5 (15.0 percent), followed by C4 (12.6 percent), C6 (11.8 percent), and T12 (7.4 percent). Of all persons entered into the SCI database, 52.9 percent are classified as tetraplegia (cervical

injuries), 46.2 percent as paraplegia (thoracolumbosacral injuries), and the remaining 0.9 percent experienced complete neurologic recovery by the time of hospital discharge. From 1979 to 1982, the number of persons with tetraplegia (or quadriplegia) peaked at 55.1 percent (see Figure 3). Since that time, from 1991 to 1995, there has been a gradual decline in the number of persons with

tetraplegia to 47.2 percent, so that paraplegia is more common than tetraplegia at the present time. This trend parallels the proportionate increase in acts of violence. Most gunshot wounds are to the chest or abdomen causing paraplegia. The decrease in tetraplegia is most likely the result of a reduction in sports related injuries which usually result in tetraplegia and the proportional increase in paraplegia caused by gunshot injuries. Interestingly, 89.7 percent of all sports injuries result in tetraplegia, while 70.3 percent of all acts of violence result in paraplegia.

Neurologic Extent of Injury

Using the *Standards for Neurological Classification of Spinal Cord Injury*, published by the American Spinal Injury Association,⁶ the extent of injury is classified as complete or incomplete. A neurologically complete injury is defined as having no preservation of motor or sensory function below the zone of injury (three neurologic segments below the lowest segment which was examined as normal). Incomplete injuries have preservation of sensory and/or motor function below the zone of injury. In-

Figure 2
Neurologic levels of injury of persons with spinal cord injury at time of initial hospital discharge.

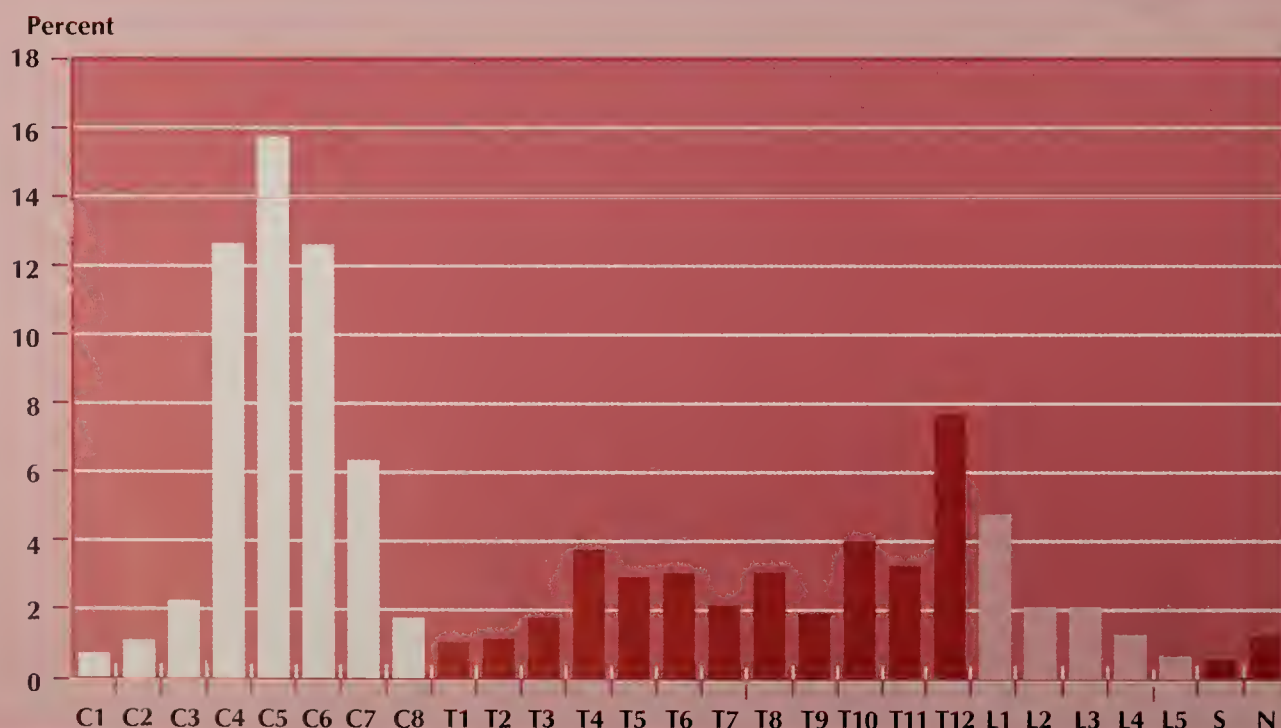
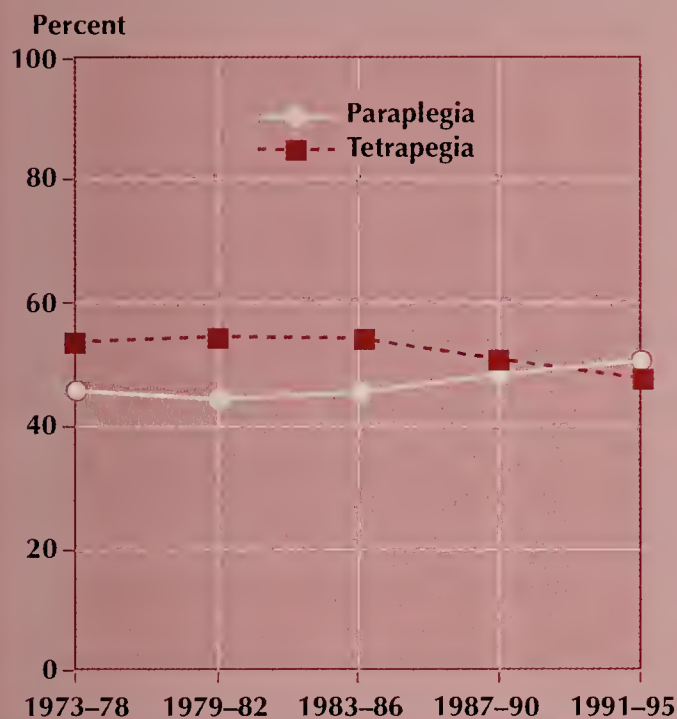
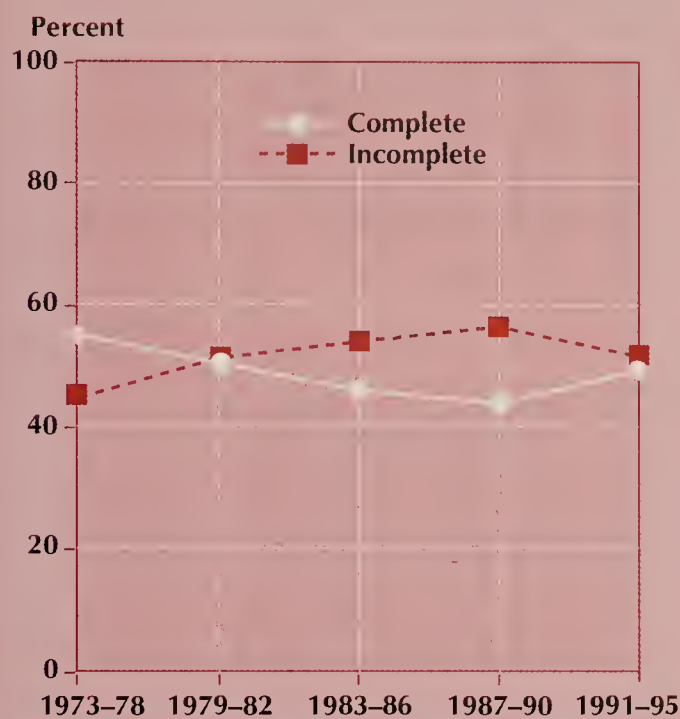


Figure 3

Neurologic levels of tetraplegia and paraplegia at time of initial hospital discharge by injury year.

**Figure 4**

Neurologic extent of injury (complete or incomplete) of persons with spinal cord injury at time of initial hospital discharge by injury year.



juries can be further subclassified by the *Frankel Grade*: A—Complete injury; B—incomplete sensory sparing only; C—incomplete, motor nonfunctional preservation; D—incomplete, motor functional preservation; and E—normal motor and sensory function.⁷ Revision of the ASIA Standards in 1992⁸ have redefined complete injury as an absence of sensory and motor function in the lowest sacral segment, however this minimal change occurred after the data analysis for most of this report.

The extent of spinal cord injury is largely dependent on the severity of the injury. The prognosis for spontaneous recovery is therefore strongly related to the presence of a complete or an incomplete injury to the nerve fibers within the spinal cord as determined by the neurologic examination. Incomplete injuries increased from 44.5 percent between 1973 and 1978 to as high as 56.4 percent between 1987 and 1990 (see Figure 4). This trend toward an increasing number of incomplete injuries can probably be attributed at least in part to improved emergency medical services at the scene of the injury and in the emer-

gency room. This is very important, since incomplete injuries have a greater chance to make further neurologic recovery and thereby have greater functional recovery as well. Between 1991 and 1995, there was a decline in the number of incomplete injuries to 51.3 percent. This decline is most likely due to a proportionate increase in spinal cord injury secondary to gun shot wounds which often occur as neurologically complete injuries in the thoracic area.

Neurologic Category

Combining the neurologic level and extent of injury provides a clearer picture of the type of spinal cord injury. The standard combination includes five neurologic categories: complete tetraplegia, incomplete tetraplegia, complete paraplegia, incomplete paraplegia, and complete recovery/minimal deficit. The most common hospital discharge neurologic category in the SCI database is incomplete tetraplegia (29.4 percent), followed by complete paraplegia (26.5 percent), complete tetraplegia (21.5 percent), incomplete paraplegia (19.3 per-

cent), and complete recovery (0.9 percent). Using grouped etiologies, the pattern of resulting neurologic categories for motor vehicle crashes is similar to that of the SCI database as a whole. Acts of violence more frequently cause complete paraplegia (42.1 percent) and incomplete paraplegia (27.5 percent). In contrast, sports accidents most often result in complete tetraplegia (42.5 percent) and incomplete tetraplegia (48.0 percent). Incomplete tetraplegia is the most common type of injury following a fall (35.1 percent). For those of advanced age at the time of injury, by far the majority have tetraplegia, with more than two-thirds of those persons having incomplete injuries.

Associated Injuries

Persons with spinal cord injury also frequently have associated injuries which are caused by the traumatic event leading to the injury. The number and severity of these associated injuries may effect the length of initial hospitalization and rehabilitation outcome. More than half (55.2 percent) of persons with

spinal cord injury have what is considered a significant associated injury.³ Fractures of the long bones are most frequent (29.3 percent) and traumatic pneumothorax or hemothorax occurs in 17.8 percent. Loss of consciousness occurred in 28.2 percent, with 18.4 percent diagnosed as having a definite traumatic brain injury. Brachial plexus injury, peripheral nerve injury, traumatic amputation, and major burns were other less frequent associated injuries.

Level of Education

The SCI database does not represent children adequately, since many children are treated in pediatric hospitals and not all of the model systems include children's facilities. Although only 2.7 percent of persons in the database are less than 15 years of age at the time of injury, 12.4 percent have education levels of eighth grade or below. The educational levels for persons with spinal cord injury are somewhat below those of persons in the U.S. general population of comparable age.³ With a median age of this SCI population of 26 years, 59.3 percent have at least completed high school. Of those between the ages of 18 and 21 years, 66 percent are at least high school graduates; however, the comparable figure for the U.S. general population is 86 percent.⁴ The percentage of persons with spinal cord injury who are at least high school graduates at the time of injury has increased over the past 20 years, perhaps due to the increased average age noted previously. This trend, however, is important since relatively lower education levels may be one of the many reasons re-employment rates after spinal cord injury are low.

Vocational/Employment Status

At the time of injury, almost two-thirds of males were working, while slightly less than half of the females were working. In addition, 1 out of 10 females was a homemaker. At the time of injury 14.3 percent of persons with spinal cord injury were unemployed.³ This rate is almost twice the average unemployment rate for the U.S. general population over the past 20 years. Be-

cause many of the model systems are in urban areas where unemployment is typically higher, the figure may be partially explained by the geographic setting. This is important because there appears to be a strong relationship between previous employment history and return to work after spinal cord injury.^{3,9} By the time of the first anniversary year after injury, only 16 percent of those working at the time of injury have returned to work. Eight percent of those initially working have entered school for more education. The educational level at the time of injury is the primary reason for the vocational status 1 year after injury. Employment rates gradually increased to reach a peak of 32 percent at about 10 years after injury for males and 33 percent at 11 years for females. The educational level of persons with spinal cord injury 5 years after injury is somewhat less than that of the U.S. population as a whole. At 10 years after injury, however, it is somewhat higher, and this is also true for 15 years after injury. These data suggest a delay as well as a prolongation of the education process in persons with spinal cord injury.

Marital Status

Because the median age of persons with spinal cord injury is rather young,

it is not surprising that most persons are single (53.5 percent) at the time of injury. Almost one-third (30.6 percent) are married, and the others are divorced, separated, or widowed. In 8 years of postinjury followup, marriages are more likely to end in divorce than expected compared to age and specific rates for the general U.S. population (44 percent vs. 23 percent).³ Of those persons married at the time of initial hospital discharge, 81.2 percent were still married 5 years after injury, compared with an expected value of 88.7 percent in the absence of spinal cord injury. Of those marriages which took place after injury, 21.7 percent terminated in separation or divorce, which is significantly higher than the 15 percent for preinjury marriages.

Community Reintegration

One of the benefits of an organized system of care for persons with spinal cord injury is their ability to return to their homes and community. In the model systems, 92.3 percent are actually discharged to private residences in their community, with only 4 percent discharged to nursing homes or custodial care facilities. This compares quite favorably with data reported by the Uniform Data System in which the percentage of persons with traumatic spinal



Hank Holman with Yash, his canine companion.

Photo by Charles Packard

Table 3
Average yearly healthcare and living expenses attributable
to spinal cord injury (in 1992 dollars)

Severity of Injury	First Year	Each Subsequent Year
High Tetraplegia (C1–C4)	\$417,067	\$74,707
Low Tetraplegia (C5–C8)	\$269,324	\$30,602
Paraplegia	\$152,396	\$15,507
Incomplete Motor Functional at Any Level	\$122,914	\$ 8,614
All Groups	\$198,335	\$24,154

cord injury had community discharges averaging 82 percent during 1990–1992.¹⁰ Furthermore, community discharge defined by the Uniform Data System included living arrangements in the home, board and care, and transitional living, whereas the model systems include discharges only to private residences. During the followup years, the percentage of persons spending any time in a nursing home declines to 1.0 percent at the time of the 15-year anniversary.

Initial Length of Hospital Stay

The average days hospitalized for acute care and rehabilitation for those in the model systems program immediately following injury has declined from 137 days in 1974 to 62 days in 1994. Until 1988, there was a gradual decline in the hospital stay to 91 days, with an

average of 3.06 less days per year during that interval period. This decline has accelerated since 1988 and has increased to 4.83 less days each year. This decline is no longer considered the result of increased efficiency during hospitalization but, rather, to be due to limitations placed on the length of hospital stay by reimbursement agencies and current healthcare policies. As expected, the initial length of hospital stay is longer for persons with higher levels of injury and complete injuries.

Rehospitalization

The frequency and duration of rehospitalization has also declined considerably since the inception of the model systems program. If one looks at a cross section of rehospitalization during the fifth postinjury year, for years

1973–75 and up to 1986–87, the frequency has decreased by 43 percent and the average number of days rehospitalized declined from 11.6 to 4.8 days. With increasing time after injury, the average number of rehospitalizations has decreased from 0.55 during years 1 to 5 to 0.32 during years 16 to 18. As aging continues, one might expect the length of rehospitalization to increase again, but this data is not presently available.

Economics of Spinal Cord Injury

The majority of the costs associated with the first year of injury are a result of hospitalization, including acute care and rehabilitation. With all charges adjusted to 1992 dollars using the medical care component of the *U.S. Consumer Index*, the mean first year charges for all persons with spinal cord injury is \$198,335 and the median charge is \$161,110¹¹ (see Table 3). Of these charges, approximately 34.6 percent are for emergency and acute hospital care, 48.3 percent for inpatient rehabilitation, and 17.1 percent for equipment, environmental modifications, attendant care, outpatient services, and other charges. Obviously, costs vary greatly according to the severity of the injury and are therefore further divided among those persons who have various levels and extent of injury. This is also true for expenses in subsequent years, averaging \$24,154, with \$74,707 for persons with high tetraplegia and \$8,614 if the person has motor functional strength at any neurologic level.

Table 4 includes estimated lifetime direct costs, discounted at 4 percent and also depending on the severity of injury and age at injury. These figures do not include any indirect costs, such as losses in wages, fringe benefits, and productivity.¹¹

Life Expectancy

Life expectancy is the average remaining years of life for an individual. Life expectancy for persons with spinal cord injury continue to increase but are still somewhat below that of persons without spinal cord injury. Life expectancy has improved dramatically

Table 4
Estimated lifetime costs discounted at 4% according
to level and extent of injury

Severity of Injury	Age At Injury	
	25 years old	50 years old
High Tetraplegia (C1–C4)	\$1,349,029	\$876,287
Low Tetraplegia (C5–C8)	\$ 748,234	\$528,021
Paraplegia	\$ 427,753	\$326,272
Incomplete Motor Functional at Any Level	\$ 287,001	\$231,018

Table 5
Life expectancy of persons who survive the first year postinjury

Current Age	Without SCI	High Tetraplegia (C1-C4)	Low Tetraplegia (C5-C8)	Paraplegia	Motor Functional at Any Level
20	56.3	32.8	38.6	44.8	49.0
30	46.9	26.8	30.7	36.7	40.5
40	37.6	20.9	23.6	28.8	31.7
50	28.6	15.5	17.0	21.2	23.4
60	20.5	11.0	11.2	13.8	15.9


over the last several decades; since the inception of the model systems program the mortality rate for persons injured between 1989 and 1992 relative to persons injured between 1973 and 1975 has decreased by 42 percent.¹² At one of the model systems,¹³ the mortality rate during the initial hospitalization was reported as 13 percent in 1972 and down to only 5 percent in 1992. Because there is a higher mortality rate immediately after the injury during acute care and rehabilitation, long-term survival can be expected to be greater if the person with spinal cord injury survives the first year. Table 5 provides a brief summary of life expectancy for those persons who survive the first year after injury.¹²

Causes of Death

Historically, renal failure was the leading cause of death among persons with spinal cord injury. Advances in medicine, including but not limited to urologic management, have resulted in dramatic shifts in the leading causes of death. Since 1973, the leading cause of death is pneumonia. This is true during the initial hospitalization as well as during the later years in life. Pneumonia is followed by non-ischemic heart disease, septicemia, pulmonary embolus, ischemic heart disease, suicide, unintentional injuries, and cancer.

With continued medical advances, one would expect that life expectancy will gradually increase and certain preventable causes of death will be decreased. Many persons with spinal cord

injury are now dying from pneumonia and cardiovascular disease, which is also true for the population of persons without spinal cord injury.

The studies reported were supported by Grant No. H123N50009 from the National Institute on Disability and Rehabilitation Research (NIDRR) U.S. Department of Education, Washington, DC. Presently there are 18 Model SCI Care Systems sponsored by NIDRR (see Table 1). 

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NEW PUBLICATIONS AND FILMS

Gendered Moods. Psychotropics and Society.

Elizabeth Ettorre and Elianne Riska. Routledge, 29 West 35th Street, New York, NY 10001-2299. Softcover: 177 pages, \$16.95; hardcover: \$55.

Gendered Moods offers a feminist analysis of the gendered character of psychotropic drug use, based on studies of long-term psychotropic drug users and the content of drug advertising. Explaining why tranquilizers are prescribed twice as often to women as men, the authors argue that gender differences in psychotropic drug use are manifestations of the gendered construction of society as a whole, and that, as a result, women are particularly susceptible to being channeled into a state of dependency on prescribed drugs.

The Ultimate Disability Handbook.

Allison Rutland Soulen, Esq., and S. Joseph Fleres. Fleres and Soulen Publications, 5565 Columbia Pike, Suite 211, Arlington, VA 22204. Toll free number: 1-800-783-6263, Ext. 1843. Softcover, 67 pages. \$19.95 plus shipping and handling. Also available as audio cassette for \$24.95 plus shipping and handling.

Written primarily for the layman, this book is also a useful guide for lawyers, physicians, and other professionals who have not dealt with problems encountered in helping persons with disabilities apply for Social Security and Workers' Compensation benefits. This publication is intended as a guide and reference on how to deal with the bureaucratic maze for persons with disability who are eligible to receive benefits.

The authors are well qualified to lend their expertise and guidance on

this subject. Ms. Soulen is an attorney in Washington, DC, who represents clients with disability claims before the Social Security Administration. Mr. Fleres is a paralegal with 15 years of experience in the area of disability benefits, including lecturing in public seminars and law schools.

The Handbook of Pediatric Audiology.

Sanford E. Gerber, editor. Gallaudet University Press, Kendall Green, 800 Florida Ave., NE, Washington, DC 20002-3695. Hardcover, 450 pages. \$75.

This publication was designed to provide professionals with a new, comprehensive resource on pediatric audiology. It provides 14 detailed chapters on every aspect of this specialty, each written by the preeminent expert in the specified discipline. Clinicians and students will learn practical, relevant techniques to use in their work with children of all ages, from infancy through elementary school. This book features the latest clinical information on cochlear implants in children, including the current debate on cultural considerations. Also, audiology and education issues are considered, along with counseling families of deaf and hard of hearing children.

This volume also includes an exhaustive bibliography and index, making it an encompassing source of practical information valuable to clinicians and students alike.

Founded in 1980, Gallaudet University Press has published more than 200 titles on deaf studies and issues. A non-profit division of the only liberal arts university for deaf and hard of hearing students, Gallaudet University Press publishes scholarly and general interest

books, children's books under its Kendall Green Publications imprint, and sign language and other textbooks under the imprint Clerc Books.

For more information and to order books, call toll-free 1-800-451-1073.

Managing Your Health Care.

Martin Gipson, Ph.D., Terry Liskevych, Ph.D, Edwin Swillinger, M.D. Pathfinder Publishing of California, 458 Dorothy Avenue, Ventura, CA 93003. Softcover, 96 pages. \$9.95.

Lots of People and organizations are involved in providing healthcare: doctors, nurses, health insurance companies, HMO's, hospitals, clinics, and others. This book helps patients and their families to get through the medical maze to obtain good medical care. It suggests ways to get the best care, avoid unnecessary treatments, and have less fear about illness.

Personality and Adversity. Psychospiritual Aspects of Rehabilitation.

Carolyn L. Vash, Ph.D. Springer Publishing Company, 536 Broadway, New York, NY 10012. Hardcover, 269 pages. \$37.95.

For this book, one of the Springer Series on Rehabilitation, the author draws upon her own experiences as a person with severe disabilities and stresses the theme of adversity as a catalyst for psychospiritual growth. Dr. Vash incorporates ideas from philosophy, religion, literature, and art to provide effective strategies for coping with disabilities. Numerous resources for further study are presented, many of which are on the cutting edge of science, health, and spirituality.

The Growth of Services for Individuals with Spinal Cord Injury

Fredric K. Schroeder

Welcome to Part 2 of a three-part series of comprehensive topics concerning individuals with spinal cord injury (SCI) and the programs and professionals that serve them. The following topics, as they relate to SCI, are covered in this issue of *American Rehabilitation*: "Vocational Rehabilitation Services," "Case Management and Critical Pathways," "Recovery Following Spinal Cord Injury," and "Assistive Devices and Empowerment Issues."

In the 1960's, RSA first initiated the development of model spinal cord injury centers and the associated Research and Training Centers (RTC's) and Rehabilitation Engineering Centers (REC's).


The model spinal cord injury centers were responsible for research, demonstration, and evaluation of a comprehensive, multidisciplinary service delivery system to improve the care, rehabilitation, and community reintegration of spinal cord injured individuals. Over the decades, these centers have grown, expanded, and improved so that now a network of these programs has been developed along with a national data base of information.

The RTC's focus on particular dimensions of a given disability such as behavioral, medical, or vocational rehabilitation considerations, and some RTC's carry out research and training activities that focus on a particular disability area such as spinal cord injury, deafness, low vision, or long-term mental illness. The REC's seek solutions to disability-related problems through technology, and their areas of investigation include sensory loss, mobility impairment, chronic pain, communi-

cation difficulties, adaption of assistive devices, and technology transfer. These programs have been administered by the National Institute on Disability and Rehabilitation Research since its separation from RSA in 1980.

Also in the 1960's, independent living centers and programs began to spring up with major expansion taking place in the 1970's and finally codified in the Rehabilitation Act Amendments of 1978, with the provision of consumer-controlled centers for independent living. The expansion of independent living services and centers continues to this day with the development of networks of centers in states and the expansion of independent living services. Many early leaders in the independent

living movement had traumatic spinal cord injuries or injuries affecting the spinal cord from polio.

As a result of the advocacy activities of centers for independent living, more and more communities are moving ahead with barrier removal, such as curb cuts and ramps to enable individuals with spinal cord injuries to have access to their communities. In addition, some progress has been made on a state-by-state basis for the provision of personal assistance services; however, as of yet no comprehensive integrated national approach exists with respect to this most important service need of individuals with spinal cord injuries. 



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The weakest ink is better than the strongest memory.

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Vocational Rehabilitation for Persons with Spinal Cord Injuries and Other Severe Physical Disabilities



*Katherine J. Inge, Ph.D., O.T.R.
Paul Wehman, Ph.D.
John Kregel, Ed.D.
Pam Sherron Targett, M.Ed.*

The 1990's must be the time when the dream becomes a reality that all persons with disabilities, regardless of the nature or severity of their disability, have the opportunity to work in the employment situation of their choice. For this to happen, there must be a renewed commitment to this goal and attention focused on developing innovative approaches for improving and expanding the provision of existing vocational rehabilitation services to individuals with spinal cord injuries and other severe physical disabilities. Unfortunately, the vast majority of people with severe physical disabilities

have not yet entered community employment and largely remain unserved (Revell, Wehman, Kregel, West, & Rayfield, 1994). They continue to experience rates of unemployment and underemployment that far exceed those of the general population, even after completing postsecondary educational and training programs (Babbitt & Burbick, 1990; Bowe, 1983; Liebert, et al., 1990). Many of these individuals could benefit from assistive technology, but they have not gained access to services and remain unserved (Mann, 1991). There are literally hundreds of thousands of people who could live and work independently with the proper application of assistive technology and supports but remain in state run institutions or nursing homes (Turner, Bar-

rett, Cutshall, Lacy, Keingham, & Webster, 1995).

According to a Louis Harris Poll of persons with disabilities, low levels of employment exist among Americans with disabilities despite the passage of the Americans with Disabilities Act in 1990. As of 1994, 68 percent (greater than two-thirds) of people with disabilities between the ages of 16 to 64 were not employed; however, 79 percent of these unemployed individuals indicated that they wanted to work, with an even greater number (84 percent) in the 16-44 age group stating that they wished to work (Louis Harris and Associates, Inc., and The National Organization on Disability, 1995).

The cost of maintaining unemployed adults with disabilities is high. Approximately 42 percent are recipients of public support funds such as Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) (Bowe, 1983). The cumulative effect of supporting large numbers of people over their lifetime is indeed substantial (Hill, Seyfarth, Banks, Wehman, & Orelove, 1987). According to the President's Committee on Employment of the Handicapped (1987), the federal government spent \$62 dollars in 1985 on subsidies, medical care, and programs for people with disabilities, more than 93 percent of whom were not working.

People with disabilities have cited that the number one barrier for not working is imposed by their disabilities. Other important barriers to employment identified by the Louis Harris Poll include the following:

- 42 percent stated that employers will not recognize that the person could do a good job;

- 31 percent were concerned about losing benefits or insurance;
- 24 percent cited unavailability of transportation;
- 24 percent expressed a need for a personal assistant; and
- 16 percent indicated a need for assistive technology.

Clearly, these are issues that should be addressed by employment programs.

Federal Policy Initiatives

Several major public policy initiatives hold promise for reversing this trend. First, supported employment, a vocational rehabilitation (VR) strategy authorized by the Rehabilitation Act Amendments of 1986, allows state VR systems to fund time-limited training and adjustment services in competitive employment for individuals who will need extensive ongoing support services to maintain their employment. This strategy has been refined and used for individuals with severe physical impairments in demonstration projects with great success (Cooper & Mank, 1989; West, Wehman, Kregel, Kreutzer, Sherron, & Sasler, 1991).

Second, PL 100-407, the Technology-Related Assistance for Individuals with Disabilities Act of 1988, provided funding to increase the availability of assistive technology services and devices for persons with physical impairments. Congress reauthorized and amended the Act in March of 1994, PL 103-218 (Technology-Related Assistance for Individuals with Disabilities Act of 1994). Two key components of this legislation include the following:

- Title I specifies that protection and advocacy services must be provided by each state in one of two ways. A state may provide funds to an already existing protection and advocacy organization, or it may request that the U.S. Secretary of Education annually reserve funds to develop a protection and advocacy organization in that state. If a state otherwise was providing protection and advocacy services as of June 30, 1993, it may continue to do so using the same plan of operation.

- Title III allows the Secretary of Education to award one-time grants to states for the establishment of alternative financing mechanisms through which consumers can obtain funds to purchase assistive technology devices and services. Each grant can be, for an amount not to exceed \$500,000 and is contingent on the state at least matching the funds.

Third, the Americans with Disabilities Act of 1990, through its broad and progressive mandates, promises to bring persons with severe physical impairments into the American work and community mainstreams. Specifically, ADA gives "civil rights protection to individuals with disabilities that are like those provided to individuals on the basis of race, sex, national origin, and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state and local government services, and telecommunications" (U.S. Department of Justice, p. 1).

In essence, this legislation has removed many of the external barriers that have interfered with the ability of individuals who have disabilities to express their choices, to exert control over their lives, and to achieve employment. In the area of employment, ADA prevents discrimination of a qualified individual with a disability if he or she is able to perform the essential functions of a job with or without reasonable accommodation; therefore, employment opportunities for persons with spinal cord injuries can now be based upon individual choice and merit rather than on the lack of knowledge or the potential misconceptions of employers. Similarly, access to the community, including public accommodations, commercial facilities, and transportation, can now be determined by the individual with a disability rather than by external factors such as availability, accessibility, or attitudes.

Fourth, the Rehabilitation Act Amendments of 1992, PL 102-569, reflects values aimed at empowering persons with disabilities. The regulations specifically address the need for consumers to have choice and control over

their rehabilitation services (Inge & Brooke, 1993). The "choice regulations" included in the amendments state that the individual with a disability must *jointly* develop his/her Individualized Written Rehabilitation Program (IWRP) with the rehabilitation counselor. The IWRP must be designed to include a statement in the individual's words describing how he or she was informed of and involved in choice related to employment goals, objectives, services, service providers, and methods used to procure or provide services. For persons with spinal cord injuries and other physical disabilities, the ability to exercise choice in a variety of situations is perhaps one of the most important accomplishments and one of the greatest benefits of ADA and the Rehabilitation Act Amendments of 1992.

PL 102-569 also refers to ADA and the Tech Act of 1988 for definitions of assistive technology, rehabilitation technology, and extended services. The Tech Act addresses the need for technology in the workplace for individuals with severe disabilities. Vocational rehabilitation counselors when assisting an individual with a severe disability must include in the IWRP "a statement of the specific rehabilitation technology services to be provided to assist in the implementation of intermediate rehabilitation objectives and long-term rehabilitation goals for the person." In addition, key report language states the following: "... the IWRP should provide for regular and periodic assessments to ensure that a match exists between the supports, the technology, and the current and changing needs of the individual who will be using the

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technology as well as other people involved in the provision of services who require the information . . . " (Senate Report 102-357, p. 39). Finally, each rehabilitation agency must:

- Describe how a broad range of rehabilitation technology services will be provided at each stage of the rehabilitation process [Sec. 101(a)(5)(C)(I)].

- Describe how a broad range of such rehabilitation technology services will be provided on a statewide basis [Sec. 101(a)(5)(C)(ii)].

- Describe the training that will be provided to vocational rehabilitation counselors, client assistance personnel, and other related services personnel [Sec. 101(a)(5)(C)(iii)].

- Describe the manner in which devices and services will be provided or worksite assessments will be made as part of the assessment for determining eligibility and/or needs of an individual [Sec. 101(a)(31)].

Consumer Involvement in Disability Program Planning

Clearly, consumer involvement in disability program planning, implementation, and evaluation has received considerable attention from consumer and advocacy groups, professionals, and policymakers (Bradley & Bersani, 1990; Gradel, 1991). DeJong, in a major address at the 1993 Annual Meeting of the American Academy of Physical Medicine and Rehabilitation, appropriately called for a "new compact" within medical rehabilitation between clinicians and disability rights advocates:

"I am urging that medical rehabilitation work toward a new alliance with people with disabilities to help forge a new sense of community at all levels of our society—local, regional, state, and national" (p. 1023).

Unfortunately, consumer choice in employment seems to remain more the exception than the rule in practice. Within Virginia, lack of consumer involvement and choices has been identified as a major problem faced by supported employment participants across all disability groups (Brooke, Barcus, & Inge, 1992). Additionally, in a recent

program evaluation of supported employment for persons with physical disabilities and traumatic brain injury (Virginia Institute for Developmental Disabilities, 1992), only 41 percent of the respondents indicated that they had exercised choice in types of jobs in which they were eventually placed, and 61 percent indicated that they did not like the jobs into which they had been placed and would like to change. These findings suggest that customer self-determination in employment is lacking for participants from these disability groups.

Good vocational rehabilitation programs must reject this old way of doing business and place customers at the center of the employment process.

As previously noted, many individuals with spinal cord injuries or other severe physical disabilities require assistive technology services and devices to enter or re-enter the competitive work force. However, as Gradel (1991) notes, accessibility and personal preferences in assistive technology are limited for many individuals with severe physical impairments. She cites data from more than 15,000 consumers responding to the National Consumer Survey sponsored by the National Association of Developmental Disabilities Councils (Jaskulski, Metzler, & Zierman, 1990) indicating that specialized services were needed by up to 40 percent of the sample. In addition, the services that are available continue to segregate and insulate consumers from other members of the community rather than integrate them with community life. Gradel further writes that most human service agencies, including employment programs, have not yet

fostered a climate of responsiveness to consumers' wants, needs, expectations, preferences, and standards.

Turner and his colleagues (1995) addressed this lack of responsiveness to the customer's needs related to technology acquisition and use. Traditionally, consumers have assumed the "client" role deferring to the authority of professionals. Turner and his colleagues stated the following:

"... many professionals view persons with disabilities as their clients whom they need to help. This professional attitude has a tendency to place the professional in the dominant role. The professional becomes the ruler and governor of agency policies, funding streams, and technical information related to assistive technology."

This very traditional approach to identifying technology has been described as one of the reasons that many consumers obtain technology only to take it home, store it in a closet, and never use the device for completing daily living and work tasks.

Good vocational rehabilitation programs must reject this old way of doing business and place customers at the center of the employment process, thus giving them choices in the labor force. To do so, service agencies need to develop a "customer service culture" that listens to its customers, involves them in service planning and delivery, and effects lifestyle changes that are valuable to them. However, there are many outdated service delivery practices that must change in order for this to happen. The following is a description of one approach to empowering individuals with spinal cord injuries and other severe physical disabilities to take control of the vocational rehabilitation process.

Developing a "Customer Service Culture"

Several demonstration projects at the Rehabilitation Research and Training Center (RRTC) at Virginia Commonwealth University have addressed the issue of developing a customer service culture. The components of these demonstrations have included the following:

- a peer-to-peer mentor program
- customer-directed career planning; and
- jobsite enabling through assistive technology, personal supports, and other accommodations.

Each of these components are interdependent; however, they will be discussed individually for clarity of presentation.

Peer-to-Peer Mentor Program: Professionals cannot understand all of the issues that an individual with a spinal cord injury or other physical disability will face when entering the workplace for the first time or re-entering after an injury. The most powerful support can only come from someone who has overcome employment barriers and achieved his/her dream. A peer-to-peer mentor program can afford customers access to individuals who have achieved what they wish to achieve. As such, projects at the RRTC have designed and implemented a process in which customers of services are matched to peer mentors of their choice.

The first activity of the peer-to-peer mentor program is a formal self-advocacy institute which occurs over a 2-3 day period. The institute introduces the customers to person-centered planning services designed to support and enhance their employment potential. Mentors and other community consumer advocates comprise the training cadre. A sample agenda is provided in Table 1.

The curriculum for the institute includes self-esteem and disability, appropriate interpersonal advocacy, rights and responsibilities, information needed for life assessment planning, and self-advocacy training. Customers learn how to exercise choices in the rehabilitation system and provide direction to those providing services. They learn skills for leading and facilitating teams, how to function proactively in the rehabilitation process by defining their own needs, and techniques for directing their own service plans. Training also is provided on key federal laws such as ADA, the Rehabilitation Act Amendments of 1992, and Social Security provisions, such as the work incentives program.

Table 1
Agenda for Project Access Peer-to-Peer Mentor Institute

Day 1

8:30 to 9:15

Welcome

Introductions and Expectations of the Training
What is a mentor?

9:15 to 10:00

Levels of Self-Advocacy

Understanding and Using Self-Advocacy

10:00 to 10:15

Break

10:15 to 11:45

Know Your Employment Rights

Title I-ADA

Questions and Answers

11:45 to 1:00

Lunch and Networking

1:00 to 2:15

Know Your Rights Under Social Security and Medicaid

Understanding SSI/SSDI

Understanding Medicaid

Navigating the Systems

Using the Systems to your Advantage

2:15 to 2:30

Break

2:30 to 3:30

Making It Happen: A Panel Discussion

Deciding to Act

Assertiveness

How to Deal with Stonewalling Situations

3:30 to 4:30

Role Play and Case Study Examples

Day 2

9:00 to 9:30

Review Activity of Day 1

9:30 to 10:15

The Rehabilitation Act and You

Being Eligible for Services

Customer Choice and Services

Client Assistance Program

10:15 to 10:30

Break

10:30 to 11:00

Supported Employment Services

What are they?

How do I use them?

What can they do for me?

11:00 to 12:00

Role Play and Case Study Examples

12:00 to 1:00

Lunch

1:00 to 2:30

Exploring the Pathway to Effective Mentoring: A Discussion

What is your vision of a mentor?

What are your expectations of a mentor

How can a mentor best meet your needs?

2:30 to 2:45

Break

2:45 to 3:30

How do we get started?

What are our first steps?

Develop an action plan.

3:30 to 4:00

Closing Activity

The overall objective of this training is to give individuals with spinal cord injuries and other physical disabilities an awareness of their rights and responsibilities in directing and participating in the rehabilitation process. The following table lists the guiding principles for these training institutes.

Customers also receive support from their mentors through various other activities to include peer support groups and one-to-one sessions in which the customer and mentor identify personal employment barriers and develop strategies that will facilitate employment. In addition, mentors are available for such activities as

- learning to navigate the public transportation system;
- talking with social security and/or other agency representatives;
- exploring funding sources for obtaining needed technology;

- visiting assistive technology vendors or attending conferences;
- accessing leisure-recreation opportunities in the community (e.g., concerts, ballgames, movies, and so forth).

While many service providers have paid professionals to perform these activities, the resource is clearly more powerful if provided by former customers of services.

Customer-Directed Career Planning and Job Placement Process: The career planning and job placement process allows project participants to explore employment options using a "customer-driven support team." This team may consist of the customer, his/her identified mentor, project staff (e.g., community support specialist, employment specialist, technology specialist, etc.), friends and family members, vocational rehabilitation counselor, Medicaid case worker, and others. The team consists

only of those individuals selected by the customer. While the project staff may feel that a particular individual should participate, he or she is not invited to attend team support meetings if this is the wish of the customer.

The team uses a person-centered approach to determine the customer's employment interests and strengths that have been described in the literature under such titles as "personal futures planning," "lifestyle planning," "MAPS," and "PATH" (O'Brien & Lovett, 1992; Pearpoint, O'Brien, & Forest, 1993). Specifically, the PATH process has been used to identify each customer's dreams and goals for employment, specify accomplishments which will occur in a 1-year time period, and establish intermediate 3-month, 1-month, and 1-week objectives and activities toward meeting the customer's career goal. Literally, the

Table 2
Consumer Institute Guiding Principles

- 1. Teaching customers with spinal cord injuries and other severe physical disabilities to understand their role as customers who can use choice as a tool of empowerment:**
 - a. assisting customers to understand their role as a customer with a right to make choices in everyday life;
 - b. encouraging customers to exercise options in choosing their rehabilitation services; and
 - c. obtaining desired employment.
- 2. Training customers with spinal cord injuries and other severe physical disabilities to be effective self-advocates by:**
 - a. understanding and using effective self-advocacy techniques;
 - b. having the knowledge to become good decision makers;
 - c. learning to be assertive and persistent when faced with stonewalling situations;
 - d. becoming skilled at the art of negotiating;
 - e. using role-play exercise to assist customers in practicing methods to obtain vocational rehabilitation and other services.
 - f. using case history assignments to teach problem solving strategies.
- 3. Training customers with spinal cord injuries and other severe physical disabilities to be mentors who are equipped to train other customers by:**
 - a. inviting customers who are experienced in using self-advocacy to initial institutes to serve as examples of good self-advocates;
 - b. use customers as trainers who can serve as role models;
 - c. have followup institutes to teach individuals to become mentors; and
 - d. have unstructured evening activities designed to encourage networking and bonding between customers that will facilitate their working together as mentors.
- 4. Empowering customers with spinal cord injuries and other severe physical disabilities by:**
 - a. teaching the value of employment to increase self-esteem, be productive, and make friends in the workplace;
 - b. training customers to know what agencies can assist them in their advocacy efforts;
 - c. training customers on ways to obtain what services they need from the establishment.

process identifies a "path" or course of action for the customers to pursue. Each customer and his/her mentor and support team are responsible for monitoring the plan and checking off the accomplishments as they occur.

Other components of the customer-directed career planning and job placement process include assisting the customer to return to preinjury employment, if this is the employment goal, or to select a new career option. This is accomplished by determining situational assessment opportunities for the customer based on his/her interests. These assessments entail identifying potential work environments in which the customer may ultimately be employed and observing him or her in the actual setting performing work demanded by that environment (Moon, Inge, Wehman, Brooke, & Barcus, 1990). Please refer to Table 3 for a "path" of one customer who has chosen to pursue a new career option and is participating in situational assessments.

An employment specialist or other identified support person assists the customer in completing these assessments in which they identify the customer's work-related support needs to include such things as assistive technology needs, wheelchair access issues, mobility and space requirements, and other critical work related issues (e.g., self-care needs, need for personal care attendant, and so forth). Please note that assistive technology needs assessment occurs within these real work environments and *not* within clinical or hospital settings. This type of *functional assessment* of a customer's needs yields valuable information that cannot be obtained in clinical settings. In addition, technology is purchased once the customer obtains employment and actual needs can be identified. Clearly, technology must be determined based on the customer's actual needs rather than on anticipated or perceived need. Table 4 lists questions that are considered when identifying potential assistive technology devices.

At the end of this phase, the customer has decided on a career goal, identified potential assistive technology devices and/or services that may

Table 3

Sample PATH Career Planning Activities for One Customer

Career Dream for the Future:

A job where I...

- can help others.
- can work around people.
- work with animals (e.g, pet store, veterinarian's office, boarding facility, park, etc.); or
- work with flowers, such as at a florist; or
- work in a department store.

1-Year Goals:

I have...

- selected a job, and I am working!
- opened a checking and savings account.
- bought new clothes with earnings.
- joined a woman's group such as the garden club.

I am...

- earning enough money to pay my own bills (e.g., long distance phone bill).
- making new friends.
- going out into the community independently (e.g, attending concerts on own, going shopping, going out to dinner, etc.)

3-Month Goals and Objectives:

I have...

- completed a situational assessment at three different worksites based on my specific interests (e.g., pet store, florist, department store).
- narrowed my job interests and choices (hopefully identified a job!).
- gone on 3-4 job interviews.
- identified where I want to go and used the accessible bus system at least 3 times by myself.
- gone to a concert with friends at least once without assistance!
- gone out to dinner with a friend at least once without assistance!

1-Month Goals and Objectives:

I have...

- picked out my interview outfit.
- identified the sites for my situational assessments.
- ridden the accessible bus system with my mentor at least once a week.
- attended regularly scheduled support group meetings.

Next Week's Activities:

I will...

- buy a day planner to keep up with my new schedule.
- talk with my personal care nurses about my job goals.
- visit at least one jobsite to begin narrowing my choices for situational assessment.
- review the want ads to get an idea about available jobs.
- role play having an interview with my mentor.
- attend a support group with other project customers.

Table 4

Considerations for Evaluating Assistive Technology Devices for the Workplace

1. Does the device assist the customer in more efficiently performing the job task that he/she is trying to complete?
2. Can the customer accomplish more of the task(s) when using the device than without it?
3. Is there a **simpler** device (low technology device) available or can one be made that will get the job task done just as efficiently?
4. Is the **appearance** of the device acceptable to the customer?
5. What is the device's **dimensions**? Will it fit within the work environment where it is going to be used?
6. If needed, is the device **portable**? (If not, does another device meet the same needs and is portable?)
7. How does the device need to be **positioned**? Can it be positioned or mounted in order for the customer to use his/her best motor response?
8. What **operating techniques** can be used with the device (e.g., direct select, scanning, encoding)? Does this match the needs of the customer?
9. What type of **feedback** does the device give (e.g., auditory click, movement when activated, tactile input)?
10. How **flexible** is the device? Can it be used with other devices used by the customer?
11. Is the device **expandable**? (Will it be useful within other environments in which the customer functions or is its usefulness limited to the workplace?)
12. Is the customer **safe** with the device?
13. What type of **warranty** is offered? Is there service available?
14. If the device breaks down, will the vendor rent or loan the customer another device so he/she can continue working?
15. Is the cost **reasonable**?
16. Can the customer or third party payer afford the cost of the device? Can the cost of the device be shared (employer, customer through a PASS plan, family, vocational rehabilitation, etc.)? Or is there a less expensive alternative that is just as effective?
17. Is the device commercially available or does it need to be custom fitted?
18. Can this device be obtained in a timely fashion? If not, can the customer rent the device until his/hers can be obtained?

(Adapted from Inge & Shepherd, 1995)

support this goal, selected a customer-driven support team, and identified a jobsite support person (employment specialist) or persons who will assist with meeting the career goal.

Jobsite Enabling Through Assistive Technology, Personal Supports, and Other Accommodations: For persons with severe physical disabilities, the term jobsite enabling is often used to describe the process of bringing specialized training,

assistive technology, ongoing support, advocacy, and consumerism to the workplace. This may be in the form of assisting the customer in completing work tasks, maintaining health and physical functioning, or contributing to a general independence or social integration. Enabling may involve the negotiation of job duties or requirements, environmental modifications for accessibility, adaptations to tools or

procedures, the use of coworkers or personal assistants, or any combination of methods as directed by the customer's circumstances, needs, and preferences. A number of these strategies are described below.

Task Restructuring: The key activities associated with a specific job may be viewed as a series of tasks and duties. A task is a specific activity (i.e., writing a memo); a duty is a group of related tasks (maintaining ongoing contact with clients). Task restructuring may be defined as the process of reorganizing or modifying the tasks or duties that presently comprise a specific job so that they more readily match the abilities of the individual with a spinal cord injury. Those tasks that are viewed as *marginal* may be eliminated. Those viewed as *essential* can be targeted for redesign and modification. Examples of task restructuring include combining duties from other jobs to create a new position (job carving), or trading off tasks that are outside the range of the consumer's abilities. Also, task restructuring may also involve changing the time of day when tasks are performed to allow the worker to coordinate key job duties with the need for personal assistance services.

Task Modification: Task modification is an essential component of the job enabling process which requires the combined efforts of the individual with a spinal cord injury or other physical disability, the employment specialist, and the employer. Task modification refers to the development of alternative methods or compensatory strategies that allow an individual to complete a specified activity. Redesigning the manner in which a task is performed, substituting construction materials, or using specialized equipment are only some of the techniques that can be used to alter the manner in which a task is performed without changing the major tasks and duties of a job. For example, as opposed to using reference books as resource guides to answer questions in a nursery, an individual in a landscape design position could convert these resources to computer files that could be

accessed by individuals using various types of assistive devices.

Assistive Technology: The availability of various forms of assistive technology may be essential to the job enabling process. The individual with a spinal cord injury must work with his or her employer to determine the amount and type of technology which will be viewed as contributing to the individual's overall productivity. The individual's employment specialist and other professionals may be very involved in

- helping determine situations in which assistive technology may enhance job performance,
- designing various "low tech" assistive devices specific to single job tasks, and
- accessing the services of rehabilitation engineers and other assistive technology specialists.

Assistive technology ranges from low tech items such as calculators or day planners to sophisticated items like speech synthesizing devices, voice recognition software, or expert system shells for specialized computer applications.

Environmental Accommodations: Environmental accommodations may involve assistive technology, but the term

refers to job enabling strategies used to improve the overall accessibility of the work station or job setting. Obvious examples of these strategies include reengineering work stations (raising height of work tables, widening doorways) for maximum efficiency. Other examples may include changing the location of an employee's work station to increase its proximity to the individual's supervisor, coworkers, or customers; improving or modifying lighting; or even allowing the individual to perform some or all of his or her duties from a home office by installing a different type of computer network and establishing electronic mail as the primary source of intra-office communication.

Providing Direct Assistance in the Job Placement Process

Some individuals with spinal cord injuries or other physical disabilities will need little or no assistance as they locate jobs that meet their career objectives. Those individuals may not benefit from specialized job placement assistance, while other individuals may view this support as valuable. It is essential that these vocational rehabili-

tation customers have access to the amount of job placement assistance and support they desire. Depending on the individual's specific needs, direct job placement assistance might include:

- assistance provided to the customer, including the development of job-seeking and resume development, referrals to employment workshops and career days, and job application assistance; and
- specialized assistance as identified in the customer's career plan, including locating a job, facilitating communication between the customer and the employer, and coordinating services provided through career centers or vocational rehabilitation.

Postemployment Follow-Along Services

Through the provision of the job placement supports described above, many customers with spinal cord injuries and other physical disabilities can succeed in meaningful and satisfying jobs of their choice. However, some may need support beyond the initial placement stage to ensure their long-term employment success. These *postemployment services* are intended to assist the customer in identifying the need for and development of accommodations (e.g., compensatory strategies, assistive devices, environmental accommodations, etc.) that can enhance the customer's learning and promote one's ability to perform independently at the jobsite. Getzel and Kregel (1996) have identified a number of guidelines to be used in the development of jobsite accommodations. Table 5 summarizes these guidelines.

Postemployment services should be designed so that the customer receives all the support he or she desires during the initial stages of employment; then the assistance is gradually removed over time as the customer becomes comfortable and satisfied in the work setting. Supports should be provided in a way that will not disrupt the relationship between the supervisor and the employee. Various types of effective supports have been designed, including tools such as

Table 5
Guidelines for Developing Jobsite Accommodations

1. Review with the customer any learner accommodations they have used previously in academic or employment settings.
2. Assist the customer in meeting with his or her supervisor to discuss the use of any type of accommodation.
3. When possible, obtain the assistance of coworkers and supervisors in the design of jobsite accommodations.
4. Seek customer input on potential strategies to use in order to enhance current performance.
5. Recognize that some strategies may be used temporarily, to facilitate learning the job. Other strategies may be used permanently, to enable the customer to perform the job.
6. Recognize that the customer is responsible for all decisions regarding the design and use of jobsite accommodations. The role of the employment support specialist is to assist the customer throughout the decision making process.

(Adapted from Getzel and Kregel, 1996)

Table 6

Employment Related Support Needs of Persons with Spinal Cord Injuries or Other Physical Disabilities

Transportation—Assistance may be needed in accessing specialized, door-to-door transportation services, acquiring vehicular modifications to allow the individual to operate a motor vehicle, obtaining driver's education, arranging car pools, or other transportation alternatives.

Housing—Assistance may be needed in obtaining affordable and physically accessible housing options, obtaining financial assistance to pay for housing costs, home modifications, and other services.

Financial Assistance—Many individuals with disabilities may be receiving SSI or SSDI benefits at the time they enter employment. Assistance may be needed in accessing and using available work incentives that allow the individual to maximize their personal income while participating in these programs.

Independent Living Services—Services that can be provided through a Center for Independent Living (CIL) include peer counseling to assist the individual in obtaining all needed services and supports, training in a variety of independent living skills, and information and referral services.

Medical Assistance—Assistance may be needed in enabling individuals to access available medical assistance, obtain supplemental health insurance, or other services.

Assistive Technology—Assistance may be needed to allow the individual to become aware of available assistive technology devices, evaluate the relative utility of various devices, and then selecting and securing devices which may aid the individual in both their employment and independent living settings.

Personal Assistance Service—Assistance may be needed in identifying the need for a personal assistant; determining eligibility for a particular personal assistant program; hiring, supervising, and evaluating the personal assistant; and funding personal assistant services.

location aids, portable cue devices (e.g., templates of routine forms, letter folding protocol, task analyses, code books, notes), electronic cue devices (e.g., computer-generated messages), visual or audio enhancements (e.g., enlarged print directories, task analysis), motor skill enhancements (e.g., handles, electronic staplers), assistive devices (e.g., modified tools, fabricated tools, specially designed, orthopedic chairs, wooden/plastic/plexiglass templates, separators), mobility aids, and protective devices.

Identifying and Obtaining Other Needed Services and Supports

An often neglected component of job enabling for customers with spinal cord injuries and other physical disabilities involves identifying the entire array of other services and supports that they may need to maintain employment. Kregel, Parent, and West (1994) found that the major obstacles impeding the ability of individuals with physical dis-

abilities to obtain and maintain employment have little to do with their performance of specific job duties and tasks. Efforts are needed to ensure that difficulties encountered by the customer in other areas such as healthcare and transportation do not impede an individual's work performance.

Most individuals with spinal cord injuries are able to advocate effectively for needed services and supports. Other customers, however, may need assistance to identify and obtain the needed supports. To address this issue, the individual with a spinal cord injury or other physical disability should work with his or her employment specialist and family members to make certain that person centered plans identify *all* needed services and supports, not just those related to an individual's employment situation. Major areas for possible support are summarized in Table 6.

To obtain the needed support services, the employment specialist and the individual may need to obtain information from a number of community

agencies. The state rehabilitation agency, the Social Security Administration, the local housing development authority, the local developmental disabilities service program, and the local or regional Center for Independent Living may all be investigated and potentially contacted for information. Transportation, residential, healthcare, and other resources should be investigated and accessed as needed to provide supports identified in the person centered plans.

Case Study Example

Client History: Peter is a 32-year-old male who sustained a C4 motor C5 sensory complete quadriplegia secondary to a gunshot wound. As a result, he is unable to ambulate and requires the use of a wheelchair for mobility. He has limited use of his upper extremities; specifically, he is not able to write or grip small objects and is dependent on others for activities of daily living.

At the time of the injury, Peter, who is a high school graduate, had been a long-distance truck driver for a moving

company. Due to the nature of his injury, Peter and his physician determined that he would not be able to return to this type of occupation. As a client of the state vocational rehabilitation agency, Peter then attended and received therapy for 3 months at a state residential rehabilitation center.

A vocational evaluation was also conducted. It recommended that Peter receive academic classes in reading, math, and spelling; consultation with a rehabilitation engineer for adaptive equipment; and reevaluation for a dispatcher position after significant improvement in academic and work tolerance was achieved. One year later, he was reevaluated and the second examiner concurred with the previous advice; in addition, a classroom program or on-the-job training as an office helper was suggested. Future evaluation was suggested if significant improvement was noted in his academic skills or physical capacity.

Approximately 2 years later in 1990, Peter was referred for a third vocational evaluation through the state vocational rehabilitation agency. When questioned if a return to his previous employer as a dispatcher had ever been pursued, Peter indicated that the job was never developed. This evaluation stated that barriers to employment included a lack of marketable skills for competitive employment without training, lack of motivation, and a lack of desire to become competitively employed. In order to remove barriers to employment training in an area that would enhance his marketable skills, counseling and motivational activities to build self-esteem were advised. It recommended that Peter return to the state rehabilitation facility for vocational training and independent living skills training and referral to rehabilitation engineering for an adaptive equipment evaluation.

Job Placement

In December 1990, Peter was referred to a supported employment program at the RRTC. Job development focused on exploring options with his previous employer. Approximately 3 months

after referral, Peter was offered part-time work at his previous place of employment as a telephone clerk for the sales department earning \$4.50 per hour. The job duties included appointment setting, telemarketing, and maintaining a mailing list.

The employment specialist assisted with identifying the *essential* job functions and required accommodations. Next, services were coordinated with the rehabilitation engineer and recommendations on possible solutions were made. The following accommodations and modifications were made for Peter.

- A computer program was designed that allowed Peter to use the computer as a means of storing and analyzing data collected.
- A headset was purchased and the telephone was attached to a box with sliding rails which allowed better access.
- A pencil was attached to a hand splint to enable him to use the keyboard.
- A lap tray was made to fit his wheelchair which allowed better access to the computer keyboard.
- A space-saver keyboard was purchased to reduce the required movements that Peter had to make to input data into the computer.

The employment specialist also was responsible for ensuring that Peter could access the various modifications introduced to the jobsite; and she provided training on the accommodations. Peter became independent in his work tasks after approximately 60 days of onsite intervention. At that point, the employment specialist began to withdraw her assistance until she was no longer present in the workplace. During the first year, the employment specialist returned to the site to assist with resolving work performance problems related to productivity and a change in job duties.

To date, the employment specialist continues to contact Peter and/or the employer twice a month in order to be proactive at identifying areas that require intervention. Most interventions have focused on updating computer software, training on the use of the software, and coordinating adaptive equipment repairs. Over the past

5 years, Peter has assumed more responsibility; currently he is responsible for maintaining daily equipment reports. The employer reports being very satisfied with Peter's performance, and Peter expresses contentment with his job.


Summary Comments

Peter's case study illustrates several important points. First, he was unsuccessful in a more traditional rehabilitation program which specified that he needed training to acquire skills *prior* to gaining employment. Although extensive evaluations were conducted, Peter remained unemployed. While many programs continue to conduct evaluations in clinical settings, Peter's case study example demonstrates that this often does not lead to employment.

Second, Peter required more intensive intervention with individualized services specific to job finding and jobsite modifications. In other words, a job placement program such as supported employment that assists the customer in finding and acquiring a job based on his or her strengths and career preferences is critical. Supported employment that has been referred to a "place and then train model," allows the customer to obtain employment and then learn the skills necessary for maintaining employment with the assistance of a job coach.

Third, Peter was able to obtain the assistance of the rehabilitation engineer in identifying and modifying the actual worksite and supplies. The employment specialist was then available to provide training on the use of these accommodations. This is of critical importance, because devices that are purchased prior to identification of the worksite can easily result in useless and unnecessary technology.

Finally, Peter has been assisted to maintain employment with ongoing support from the employment specialist. Not every customer will need this ongoing assistance, but it has been beneficial to Peter. For instance, the employment specialist has worked with him and the employer to negotiate time

off from work due to ongoing health-care needs when Peter has pressure sores. In addition, he receives ongoing training in new work tasks as well as in new worksite modifications, which continues to make the difference for this customer with a spinal cord injury. 

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Recovery Following Spinal Cord Injury



Spinal cord injury (SCI) is one of the most devastating injuries an individual can sustain. Of paramount concern to patients and their families is what degree of return of function they can expect. This paper will review the general recovery of motor function as well as recovery of ambulation and other activities of daily living following a spinal cord injury.

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In order to adequately assess recovery following spinal cord injury, it is necessary to have a common, reliable, and valid way of measuring recovery. A basic understanding of the anatomy of the spinal column, spinal cord, and motor and sensory nerves is needed to understand the components of the measurement tool.

The spinal cord consists of a central gray matter and surrounding white matter. The white matter contains the descending (motor) and ascending (sensory) tracts. These spinal tracts transmit information between the brain and body. The gray matter represents the neuronal cell bodies and is organized in a segmental manner with spinal nerves entering and exiting through the vertebral foramina. The roots are numbered and named according to their point of entry into or exit from the vertebral column. The roots receive sensory information

from specific areas of skin called dermatomes. The term myotome refers to the group of muscles innervated by a specific root. Most roots, however, innervate more than one muscle, and most muscles have multilevel innervation.

In a spinal cord injury, transmission of motor and/or sensory information across the site of the lesion is interrupted or impaired. The cause of injury may be due to a vascular insult to the cord or to contusion or bruising of the cord, but violence or high velocity trauma such as motor vehicle accidents are the most common causes in the United States. The degree of motor and/or sensory

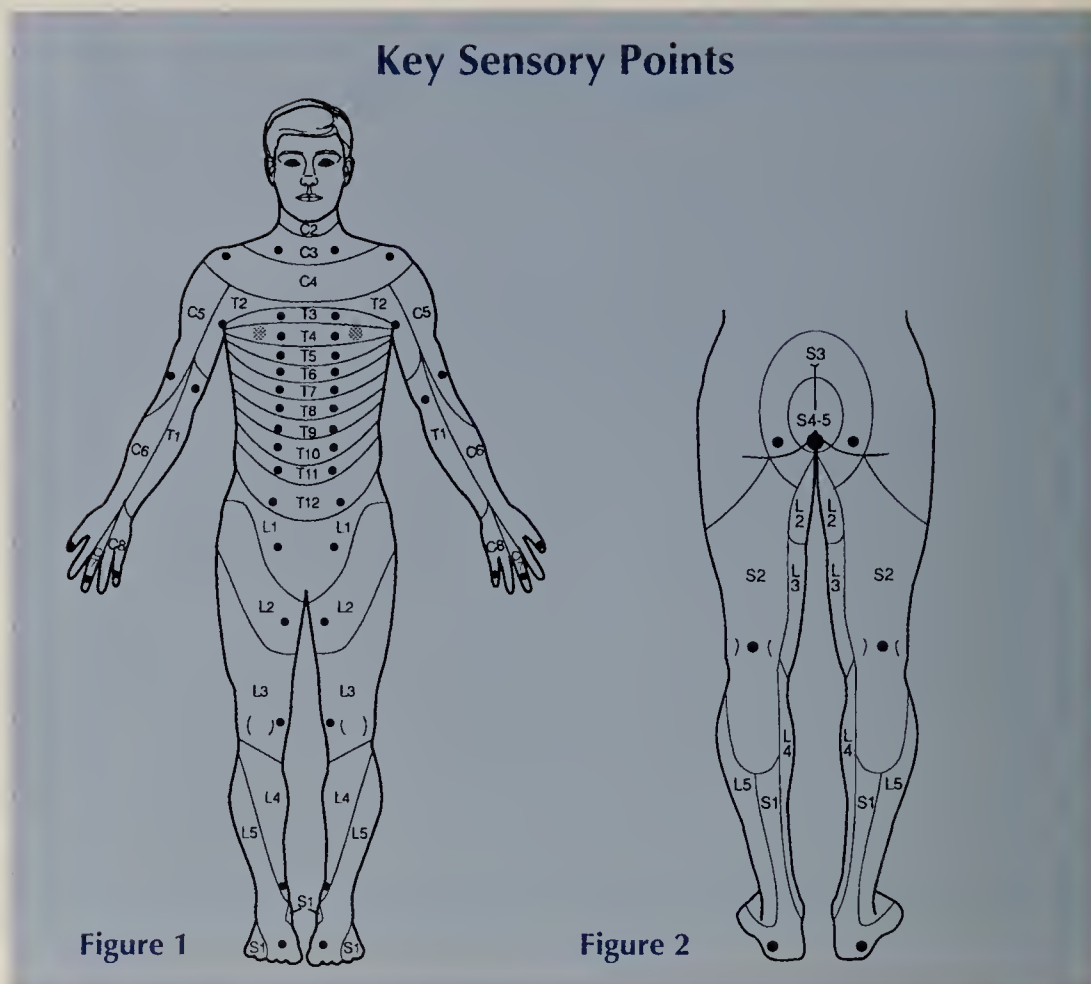
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loss is determined by the location and severity of the cord damage.

If the lesion is in the cervical segments of the cord, impairment of function in the arms, legs, trunk, and pelvic organs results. This is known as tetraplegia, although the term quadriplegia has also been used. Paraplegia refers to a lesion in the thoracic, lumbar, or sacral segments of the cord. Patients with paraplegia have normal arm function. Depending upon the level of the lesion, the trunk, legs, and pelvic organs may be affected. In addition to the general level of injury, i.e., tetraplegia or paraplegia, a specific neurologic level can often be identified by performing a detailed neurologic examination. The completeness of the injury can also be determined by neurologic examination. The term "incomplete" injury refers to partial preservation of sensory and/or motor function in the lowest sacral segments of the cord. A "complete" injury is one in which there is no preservation of function in the lowest sacral segments.

In 1982, the American Spinal Injury Association published guidelines for neurological classification of spinal cord injuries. The guidelines were revised in 1992, and the *Standards for Neurological and Functional Classification of Spinal Cord Injury* were subsequently endorsed by the International Medical Society of Paraplegia (ASIA, 1992). The ASIA standards represent the most valid, precise, and reliable data set to assess SCI and are used by the National Model System Spinal Cord Injury Database.

Prior to the publication of these guidelines, there was no universally accepted classification system for measuring the severity of SCI. Therefore, it was difficult to compare outcomes among different studies and it was difficult for physicians to accurately communicate among themselves when tracking patient progress. The system most commonly used prior to the acceptance of the ASIA standards was the Frankel score or the modified Frankel score (Frankel, et al., 1969). In this system, patients were divided into five broad categories based on neurologic deficit. This system, however, was insensitive to patient changes within



each category and utilized broad categories that were not well defined.

The neurological examination as recommended in the ASIA standards consists of both sensory and motor examinations. Sensation to both pin prick and light touch is assessed bilaterally at key points on the body representing each of the 28 dermatomes, which in turn represent the neural segments from C2 to S5 (see Figures 1 and 2). Sensation is assessed on a three-point scale with 0 designating absent sensation, 1 representing impaired sensation, and 2, normal sensation. Anal sensation is tested and sacral motor function is assessed by whether there is contraction of the external anal sphincter when the examiner's finger is inserted. Determination of anal sensation and contraction is necessary to determine the completeness of injury.

The motor examination is conducted by manual muscle testing of 10 key muscles on each side of the body. These muscles represent the myotomes for neural segments representing the arms (levels C5 through T1) and legs (levels L2

through S1). The strength of each of the 10 key muscles is graded on the standard 6-point scale (0=absent, 1=trace, 2=poor, 3=fair, 4=good, 5=normal).

Motor and sensory scores provide a quantitative representation of neurologic deficit. The ASIA Motor Score (AMS) is the sum of the strength grades for all 10 key muscles bilaterally. Thus, in an individual with no motor deficit, the total score would be 100. The sensory score is the sum of the sensory grades for each dermatome.

The neurological level of injury (NLI) is the lowest level of the spinal cord with normal sensory and motor function bilaterally. Because segments with normal function can vary by modality (sensory vs. motor function) and side of the body, up to four different segments can be identified: right-motor, right-sensory, left-motor, and left-sensory. Frequently, however, patients' neurological deficits are designated by a single motor level and a single sensory level.

Immediately following injury it is often difficult to perform an accurate neurological examination. The patient

may be sedated, intoxicated, confused, or in pain. In addition, the patient may be undergoing acute medical or surgical stabilization. The obstacles to performing an accurate neurologic exam in the immediate postinjury period make it difficult to assess the effectiveness of early interventions such as surgery or drugs. The difficulty of performing an accurate examination in the acute postinjury period is, however, not a liability in obtaining predictors of recovery, since performing the neurological exam between 72 hours and 1 week following injury provides more accurate predictors of short-term recovery than when the exam is performed within the first 24 hours following injury.

When a patient undergoes sequential neurological examinations, the differences in motor and sensory scores between successive exams is representative of the recovery (or deterioration) that has occurred in the intervening time. By dividing the difference between scores by the number of intervening days, the change per day can be determined. Finally, by multiplying the change per day by 365, the annualized rate of change can be calculated. The annualized rate represents the rate of change during a particular interval that would have been expected if it were to

have continued for 1 year. In general, recovery of sensation follows a pattern similar to that of motor recovery. Therefore, in this paper we will focus on motor recovery.

Recovery will be addressed in specific categories of patients. These findings are based on an 8-year prospective study funded by the National Institute on Disability and Rehabilitation Research and executed at Rancho Los Amigos Medical Center in Downey, California. This study constitutes the largest prospective investigation (over 500 cases) to determine the patterns of recovery conducted to date.

Bracken, et al. (1990) reported that recovery after spinal cord injury was significantly enhanced when methylprednisolone was administered within 8 hours following injury. Although the study was well designed, randomized, and controlled and included a large number of subjects, the results remain somewhat controversial. The differences in motor and sensory scores were significant but small. Additionally, when the randomized groups were closely examined, some biases which could affect outcomes were noted. Due to ethical and legal implications, it is no longer feasible to replicate the Bracken study or to test the effectiveness of other

pharmaceutical interventions on recovery without including the administration of methylprednisolone. None of the patients in the Rancho study had received methylprednisolone following injury.

Recovery after spinal cord injury was significantly enhanced when methylprednisolone was administered within 8 hours following injury.

Complete Paraplegia

In a report on 142 individuals with complete paraplegia, none with an initial neurologic level (NLI) above T9 recovered any lower extremity (LE) function 1 year following injury. Although 38 percent of those with an NLI below T9 had some recovery of LE function, only 5 percent recovered sufficient hip and knee strength to ambulate using conventional orthoses and crutches. Additionally, all of the patients who regained ambulatory function had an NLI at or below T12. Four percent of individuals who were assessed as having complete injuries at admission converted to incomplete status. Half of these patients who underwent late conversion to incomplete status regained bowel and bladder control (Waters, Yakura, Adkins, & Sie, 1992).

Recovery Following Incomplete Paraplegia

Individuals with incomplete paraplegia demonstrated an average gain of 12 lower extremity motor score (LEMS) points 1 year following injury. Amount of recovery was not dependent upon NLI. Final motor status, however, was dependent upon NLI because individuals with NLI's above T12 had lower



average initial LEMS's than those with NLI's at T12, who in turn had lower initial LEMS's than patients whose NLI's were below the T12 level. Seventy-six percent of the 54 individuals with incomplete paraplegia were able to ambulate in the community 1 year following injury (Waters, Adkins, Yakura, & Sie, 1994a).

Brown-Sequard injuries are a subset of incomplete injuries which occur when either the right or left side of the spinal cord is damaged. This type of spinal cord lesion results in diminished muscle strength and joint position sense on the same side of the body as the cord damage and loss of pin prick sensation on the side of the body opposite the cord lesion. These individuals usually have a favorable prognosis for recovery but few demonstrate the classic syndrome. Although these individuals frequently recover some motor function, significant residual spasticity usually interferes with function.

Recovery Following Complete Tetraplegia

Individuals with complete tetraplegia demonstrated an average AMS increase of nine points in the interval between admission and 1 year following

injury. The initial AMS increased as the NLI's progressed from C4 to C8, but the average total point recovery did not vary. Thus, amount of recovery was independent of the initial NLI, but final absolute AMS was dependent on NLI. No individuals with complete tetraplegia were able to ambulate at followup (Waters, Adkins, Yakura, & Sie, 1993a).

Recovery Following Incomplete Tetraplegia

The motor recovery rates for individuals with incomplete tetraplegia do not differ significantly between the upper extremities and the lower extremities. Furthermore, recovery in the upper and lower extremities occurred concurrently. Forty-six percent of individuals with incomplete tetraplegia were able to ambulate in the community 1 year following injury.

Investigators have determined that individuals who are incomplete only by virtue of retained pin prick sensation sacally have a better prognosis for lower extremity motor recovery than those who have only light touch sensation. Thus, sacral sensation is an important variable when predicting motor recovery.

Within this category of tetraplegia there are two specific incomplete syndromes with characteristic motor and sensory loss patterns. Anterior cord syndrome results in loss of motor function and pin prick sensation with retention of light touch sensation and joint position sense. Motor recovery in these individuals is similar to that in individuals with complete neurological injury. Central cord syndrome frequently occurs in older individuals as a result of hyperextension of the neck. In this syndrome, motor loss is more severe in the upper extremities compared to the lower extremities. These individuals often recover the ability to ambulate but retain weakness in their upper extremities (Waters, Adkins, Yakura, & Sie, 1994b).

Timing of Recovery

Graphic representation of annualized rates of recovery vs. time since injury have demonstrated that the rate of motor recovery rapidly decreases as time since injury increases (see chart). The greatest recovery occurs in the first 6 months following injury with a plateau in rate of recovery occurring at approximately 9 months postinjury.

Functional Recovery

When a muscle is able to move a body part through the full range of motion against the force of gravity it has attained at least grade 3 of 5 and is considered functional. The strength of a muscle at 30 days was found to be predictive of recovery to a functional level (Waters, Adkins, Yakura, & Sie, 1995a). When muscles with a 30 day initial grade of zero and those with an initial grade of 1 or 2 were compared, a smaller percentage of 0 grade muscles recovered functional strength compared to muscles with an initial grade of 1 or 2. (Table 1). For example, 73-100 percent of individuals with incomplete injuries and initial muscle grades of 1 or 2 recovered to at least grade 3 by 1 year compared to 20 to 26 percent of those with 0 grade muscles.

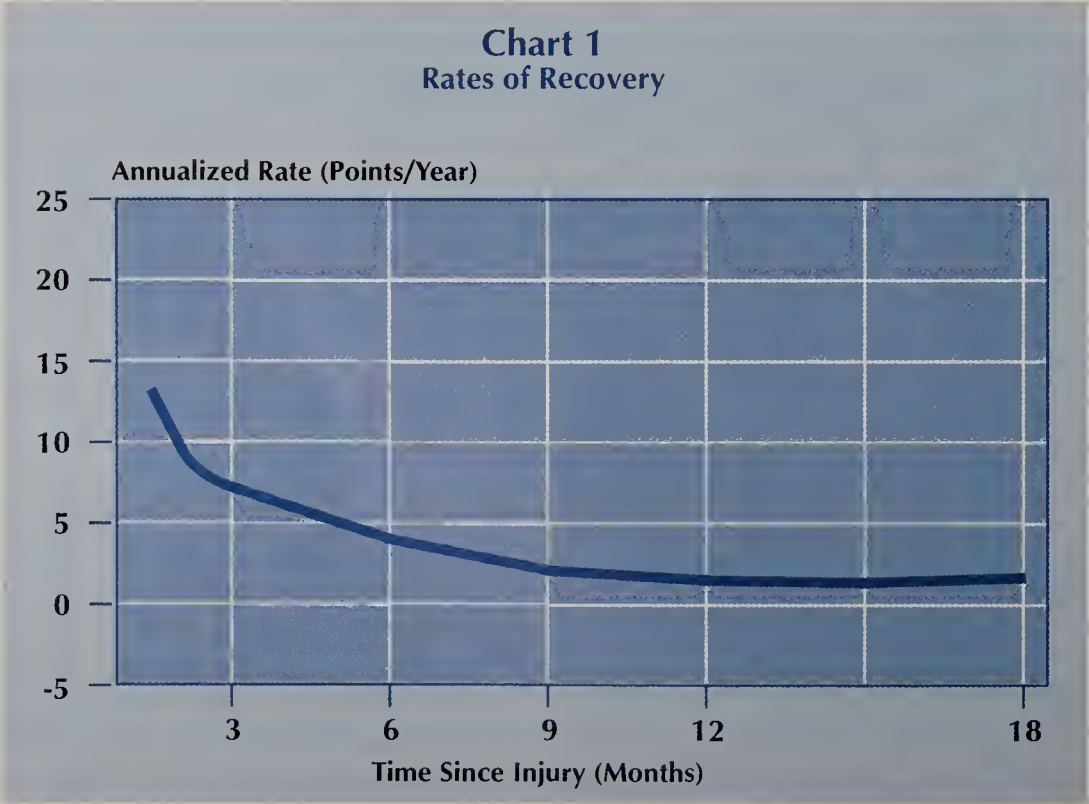


Table 1
Recovery to Grade 3/5 or Higher at One Year Following Injury
 (% of muscles tested)

Injury Category	Strength at 30 Days	
	0/5	1/5 or 2/5
Incomplete Injuries	20–26%	73–100%
Complete Tetraplegia	4–22%	97%
Complete Paraplegia	4–8%	68–70%

Ditunno and colleagues (1991) found that recovery to at least grade 3/5 in the elbow flexors and extensors and the wrist extensors was more likely if the individual demonstrated voluntary motor function in those muscles 1 week following injury. They also reported that recovery of wrist extensors could

be predicted from the initial strength of the elbow flexors (Ditunno, Sipski, Posuniak, Chen, Stass, & Herbison, 1987).

Recovery of a specific functional task is dependent upon the neurological recovery that an individual attains. Individuals with incomplete spinal injuries can have a wide range of sensory and

motor function despite having the same neurological level of injury. For example, a patient with a C5 incomplete injury may have decreased motor function in the lower cervical myotomes but may have lower extremity muscles that are all present, although weak. This patient would have a more favorable prognosis for ambulation and other activities of daily living than another patient with an identical neurological level of C5 incomplete who had only spared sensation but no motor function. Because of this variance in function it is difficult to predict function based on level of injury in incomplete injuries.

Guidelines for expected level of function have, however, been developed for individuals with complete spinal cord injuries. Predictions about mobility, transfers, and self-care can be made

Table 2
Expected Function According to Level of Injury
Complete Tetraplegia

Neurologic Level	Mobility	Transfers	Self-care
C1–C3	Possible candidate for electric wheelchair with portable respirator and tongue switch/breath control.	Dependent requiring a lift.	Dependent.
C4	Electric wheelchair with chin or tongue control.	Dependent requiring a lift.	Dependent.
C5	Electric wheelchair with hand control or possibly, manual wheelchair with handrim projections (pegs).	Dependent.	Assisted with light hygiene and self-feeding with proper equipment.
C6	Manual wheelchair with friction surface handrims. May require electric wheelchair for use in community.	Independent with sliding board and proper equipment.	Independent in UE activities with proper equipment. Independent when assisted with LE dressing and bowel/bladder management.
C7	Manual wheelchair may require friction surface handrims.	Independent with sliding board.	Independent with proper equipment.
C8	Manual wheelchair may require friction surface handrims.	Independent.	Independent.
T1	Manual wheelchair with standard handrims.	Independent.	Independent.

Adapted from Adkins, R.H.: Spinal Cord Injury Capabilities and Consideration According to Level of Injury (unpublished).

Table 3
Expected Function According to Level of Injury
Complete Paraplegia

Neurologic Level	Mobility	Transfers	Self-care
T1-T8	Manual wheelchair with standard handrims.	Independent.	Independent.
T9-T12	Manual wheelchair. Some T12 may ambulate.	Independent.	Independent.
L1-L2	Manual wheelchair. May be household or limited community ambulator with crutches and orthoses.	Independent.	Independent.
L3-L5	May be community ambulator with proper equipment and training.	Independent.	Independent.

Adapted from Adkins, R.H.: Spinal Cord Injury Capabilities and Considerations According to Level of Injury (unpublished).

when a patient's neurologic level of injury is known (Tables 2 and 3).

Ambulation

Restoration of walking remains one of the most important issues for patients. In general, a minority of individuals with SCI are able to resume walking following an injury. The level and completeness of injury does, however, influence the ability to ambulate. As previously stated, no patients with complete tetraplegia regained their ability to walk. Only 5 percent of those with complete paraplegia were able to walk 1 year following injury compared to 46 percent of those with incomplete tetraplegia and 76 percent of those with incomplete paraplegia (Waters, Adkins, Yakura, & Sie, 1994b).

The ASIA lower extremity motor score is also predictive of ability to walk. The total possible LEMS in an individual with no neurological deficit is 50 points. Individuals with a LEMS of 30 or more attained community ambulation status 1 year following injury. In contrast, those with a LEMS of 20 or less who were able to ambulate were

able to do so only on a very limited basis. These individuals walked at much slower average velocities while demonstrating a greatly increased physiologic energy expenditure. Furthermore, early measurement of LEMS can also be used to predict ambulatory function. When the LEMS is determined at admission to the rehabilitation center and patients are grouped by level and completeness of injury, the proportion who are able to walk 1 year following injury increased as the initial LEMS increased.

Recovery Research


Using the methods outlined at the beginning of this report, neurological recovery has been studied in specific patient groups (individuals with spinal cord injury due to spondylosis, stab wounds, spinal cord infarct, or gunshot wounds) to determine if unique recovery patterns can be differentiated based upon etiology of injury or treatment (Waters, Adkins, Yakura, & Sie, 1991, 1993b, 1995b, 1995c, submitted). The effect of anatomic pattern of injury on recovery has also been stud-

ied. The overall result of these investigations has been that the neurological level and completeness of injury at 30 days is the best predictor of recovery. Once the neurological status of the injury is known, the etiology and anatomic pattern of injury add no predictive power for recovery.

Summary

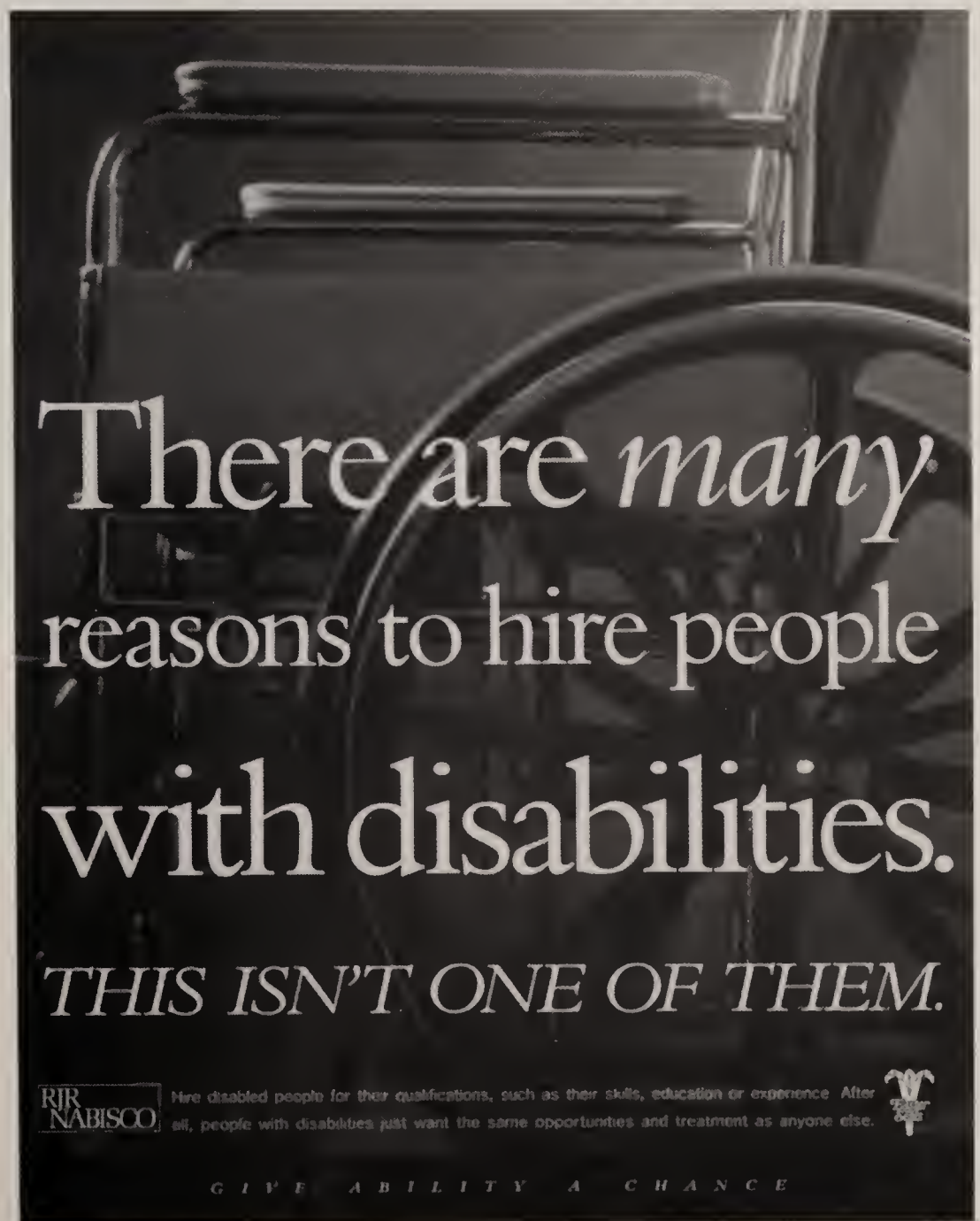
A detailed neurological examination performed approximately 1 month following injury currently provides the most reliable predictors for recovery of spinal cord injury. The majority of motor recovery that can be expected occurs within the first 6-9 months. At approximately 9 months the rate of recovery plateaus.

Acknowledgements

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G I V E A B I L I T Y A C H A N C E

Case Management and Critical Pathways: Links to Quality Care for Persons with Spinal Cord Injury

Changes in the healthcare environment and reimbursement practices have resulted in profound restructuring of traditional healthcare delivery and practice patterns throughout the country (Messler, 1994). The development of systems of cost-effective quality health service is the challenge the healthcare industry faces. One such system, a frequently used model of nursing care delivery in acute care settings, is case management (American Hospital Association, 1990). The purpose of this article is to share our approach to the development of this innovative system.



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At the Medical College of Virginia Hospitals/Virginia Commonwealth University (MCV/VCU), the development and implementation of a case management/critical pathway system grew out of a desire to improve patient care services to patients with spinal cord injury (SCI).

Overview of Case Management/Critical Pathways

Case management is designed to promote patient and customer satisfaction

through the use of clinically expert case managers who can balance patient and family needs with efficacious and cost-effective use of resources while continually monitoring, evaluating, and modifying the treatment plan to achieve optimal patient outcomes (Mercy Healthcare Arizona, 1994). The goals of case management are to optimize patient self-care, decrease fragmentation, provide quality care across the continuum, enhance quality of life, and promote the effective use of resources.

A review of the literature demonstrates that case management has become a synonym for cost-effective quality care (Girard, 1994). Case management has been implemented by many health-

care agencies and professionals across various practice settings. It has proven to decrease length of stay and provide quality care within cost constraints (Sterling, 1994). The complex needs of the spinal cord injured patient warrant the coordinated, timely efforts of many human and material resources within different practice settings. The delivery of such care is likely to be disjointed, and outcomes of care less than optimal (Bejciy-Spring, 1994), hence the natural place for a case manager to support care transitions and team communication.

Under the traditional healthcare delivery system, the provision of care to the SCI patient is often a complicated, cumbersome, time consuming process that lends itself to a case management approach (Strong, 1991). The literature clearly demonstrates that case management has been successfully implemented for patients or populations who have significant needs, have predictably unpredictable hospital stays, and are high volume and high cost (Girard, 1994). It has been suggested that case management of the SCI patient could serve as a means to enhance quality rehabilitation outcomes, increase patient satisfaction, enhance interdisciplinary relationships, and improve continuity from intensive care to community settings (Bejciy-Spring, 1994). Currently, however, there are no studies that demonstrate the effectiveness of a case management approach to the spinal cord injured patient population.

One aspect of the case management approach involves the development of critical pathways. A critical pathway is an interdisciplinary document that communicates planned interventions for a specific population within a specific timeframe (Mercy Healthcare Arizona, 1994). Pathways organize, sequence, and time "critical" patient interventions (Bergman, 1994).

Critical pathways:

- reduce variations in treatment (Lumsdon, 1993);
- are educational tools for new practitioners;

- reduce re-work and redundancy in care;
- assist with quality improvement work;
- decrease fragmentation in care, which is possible with complex populations such as SCI;
- strengthen collaborative practice and improve teamwork;
- are outcome focused and quality driven;
- allow for the analysis of services to the patient; and
- prevent gaps or delays in required patient services.

The most important goal of case management and the use of critical pathways is to improve patient outcomes. Implementing clinical pathways and analyzing the variance data from pathways are key to reaching expected outcomes, timely discharge of patients, and appropriate utilization of resources. Data such as this would be particularly helpful with the complex medical and treatment issues of patients such as those with spinal cord injury.

We found ourselves with "units" caring for SCI patients when what we wanted was a seamless continuum of care.

The Environment

MCV/VCU, a 700-bed urban university medical center located in the heart of Richmond, Virginia, is a Level 1 trauma center and a federally designated regional model system of care for patients with traumatic brain and spinal cord injury. Contained within the MCV complex is the complete continuum of care for patients with SCI, including a state-of-the-art neuroscience intensive care unit, a neuroscience progressive care unit, a neurosurgery unit, and a CARF-accredited SCI rehabilitation program.

Early in 1991, the nursing director of the Neuroscience Center proposed that the spinal cord injury program be examined for opportunities to improve services. An invitation was extended to the medical director of the spinal cord injury service to co-lead the efforts for improved services. With the medical director's acceptance of the co-leader role, an interdisciplinary group was formed to begin the work of improving services to SCI patients.

The Climate for Change

At the same time the nursing and medical directors were forming a group to improve spinal cord injury services, three major organizational initiatives were in development. These initiatives, which included the development of *Product (Service) Line Management*, continuous quality improvement, and managed care, provided additional momentum to improve the continuum of services for SCI patients.

Product (Service) Line Management is a method to integrate all disciplines involved in the production of a specific product, such as spinal cord injury care. It provides a framework for ongoing monitoring and analysis of the work being undertaken, it is amenable to changes in the market place, and it is best developed by the service provider. The key is to foster vertical and horizontal integration within the system (O'Malley, 1991). We found ourselves with "units" caring for SCI patients when what we wanted was a seamless continuum of care. Service lines allowed us to all focus on the single product: excellent patient outcomes for SCI patients.

Service line management is collaborative, multidisciplinary, and always customer focused, and it attempts to

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group related services to satisfy the customer. The success of a service line perspective is directly related to the organization's ability to focus on the needs of the patients and how those needs are marketed and priced (Flynn, 1991).

Continuous Quality Improvement (CQI) is a tool to analyze service delivered to specific customer groups and to find ways to deliver that service more effectively. It allows the observation of patient care initiatives with a careful analysis of the accuracy, completeness, correctness, cost, and timeliness of interventions. Areas where there is a gap between what is desired and what is delivered can be corrected (Kralovec, 1991). By using the pathway to look at SCI care, we are able to perform just such a quality analysis.

In managed care strategies, the provider of service teams up with the payor in ways that produce quality care in a cost-effective way. The goal of man-

aged care should not be thought of only in financial terms. Rather, the goal is to maximize the value of a service: the quality delivered for the costs incurred (Hicks, 1992). Again, using the pathway as a CQI tool, we could examine the value of the service we delivered, recognize the areas where we needed to improve, and support these initiatives with data.

Creating the Vision

As with most projects or plans, it is prudent to begin with a vision of how the product should appear once completed. The vision should then guide the decisions made in each step of the process.

The MCV/VCU interdisciplinary SCI team began with such a vision, which was formed by asking the team two questions:

- What should our spinal cord injury customers be able to expect from a service perspective when they enter the MCV spinal cord injury program?

- How can quality service be assured through the MCV continuum of care?

It was decided by the group that patients should be able to expect the following:

- adequate information regarding SCI;
- involvement in the planning of care;
- smooth and timely transitions within the continuum;
- freedom from hospital acquired problems; and
- care from a highly skilled team.

A necessary step in bringing the vision to reality was a thorough discussion of the current program: its strengths and its weaknesses.

The program's strengths included:

- the existence of a highly skilled team of professionals with expertise in the care of patients with spinal cord injury

- strong communication links within the acute and rehabilitations teams.

Weaknesses included:

- unclear service delivery goals,
- fragmented patient transitions, and
- the lack of an interdisciplinary focus across the continuum of care.

Examination of the current spinal cord injury program led to productive discussions regarding ways to address problems. The dominant issue was how to link the improvements in the program in a way that would most effectively meet the needs of patients.

The nursing director of the Neuroscience Center suggested the development of a critical pathway as a framework for coordinating care across the continuum and as a tool for program development. This innovative strategy for improving patient care was just beginning to be addressed in the literature as the MCV team was forming. Critical pathways had been developed in predictable illnesses, such as coronary artery bypass; however, pathways on traumatically injured patients—such as SCI—had not yet been developed.

Development of the Pathway

Pathway development involved an 18-month process of *education, negotiation, collaboration, and communication*, which began with education of the interdisciplinary team regarding the elements and purposes of a critical pathway. Most of the team members were unfamiliar with the critical pathway concept; the educational process was therefore necessary in beginning our work.

Following the education process, negotiation began on the layout of the pathway. Because the process of care varies for the acute and rehabilitation phases of a patient's hospital experience, such things as the titles of each section (i.e., systems vs. function) of the pathway and the timeframes (daily goals vs. weekly goals) had to be determined through negotiations with the team.

The most challenging phase of the development of the pathway came with the decision on which "critical" interventions to include in the pathway and

the timing of those interventions. As healthcare professionals, we wanted to include every detail of care as critical. This, however, would have made the pathway much too cumbersome for use.

The pathway development team attempted to use the current literature to guide the development of the interventions for the pathway. While the literature reflected the current standard of care for spinal cord injury, it did not contain information on the interventions that were crucial in moving the patient toward important outcomes. In addition, the literature provided no specific information on the timing of the standard interventions for patients.

In view of the lack of literature, the team pooled its collective expertise to decide upon the critical interventions and the timing of these interventions. This effort required hours of collaboration, negotiation, and communication. Countless hours of work resulted in an interdisciplinary document that would hopefully guide SCI patients within our system toward positive outcomes.

Implementation/Pilot Project

Implementation of the SCI critical pathway began in July 1992 and included a 6-month pilot project to determine the efficacy of its use. The plan required several important steps.

Education was the key component in the first phase of the implementation. All disciplines were given inservice training on the purposes and use of the pathway for SCI patients. The process was made easier because, during pathway development, the team members communicated with their respective disciplines regarding the upcoming implementation of the tool and the need for their input.

Once the pathway was in use, the neuroscience clinical nurse specialist worked with staff on the units within the continuum to resolve issues with implementation. One important issue involved the recording of variance data and how that process should occur. In addition, logistical issues, such as where to keep the document and how to get it printed, needed to be addressed.



The implementation process/pilot project required continual feedback. The SCI critical pathway was the first pathway implemented at the hospital, therefore the staff had no frame of reference from which to work. The entire interdisciplinary team played pivotal roles in integrating the document into the care of the spinal cord injury patients through demonstration of the use of the tool as they delivered care and through feedback to their peers.

Evaluation

Evaluation of the effectiveness of the critical pathway occurred in several ways. First, data was collected to examine if there were differences in the length of stay and cost between patients placed on the pathway during the pilot project and those that had been patients prior to the implementation of the pathway. Significant decreases in length of stay and cost were noted in the postimplementation groups. In particular, length of stay in the Intensive Care Unit was decreased by 14 days and cost was dramatically reduced.

The examination of variance data was a second level of evaluation that occurred in the postimplementation phase. All of the pathways were reviewed and variances examined. Pain management was noted to be an important variable in whether or not SCI patients progressed steadily toward their goals. This data was confirmed by clinicians who had had numerous encounters with pain management issues with patients. As a result of the pathway variance data, pain management has received more attention in spinal cord injured patients.

During the evaluation phase, the nursing staff identified the need for a "champion" of the process who would assure unit and continuum monitoring of pathway use. It was at this point that we added the role of unit-based SCI case manager to the program. Through collaboration and discussion with the interdisciplinary team, a model for the implementation of case management was conceptualized. The model links the continuum of care, data analysis, and the process of improving organizational outcomes by using a contin-

uum case manager and a unit-based case manager (see illustration).

Benefits of the Process

Certainly, the evaluation data noted above indicate some of the positive influences that the use of critical pathways can have for the organization and, most importantly, for the patient. However, it is the unmeasurable benefits of going through the development process that may have a more lasting impact on the overall quality of the spinal cord injury program. For the MCV team these included increased knowledge, an improved interdisciplinary approach to the patient, and increased team cohesion.

Prior to the development of the pathway, each of the team members were expert clinicians in their own phase of care delivery. However, after the process of pathway development each team

member believed that they had gained a broader knowledge of spinal cord injury care. The team members from the acute phase of care came to understand the important rehabilitation concepts that needed to be integrated into the acute care of the patient. Rehabilitation team members gained knowledge of the acute management of patients that was helpful to them in managing acute issues occurring in rehabilitation.

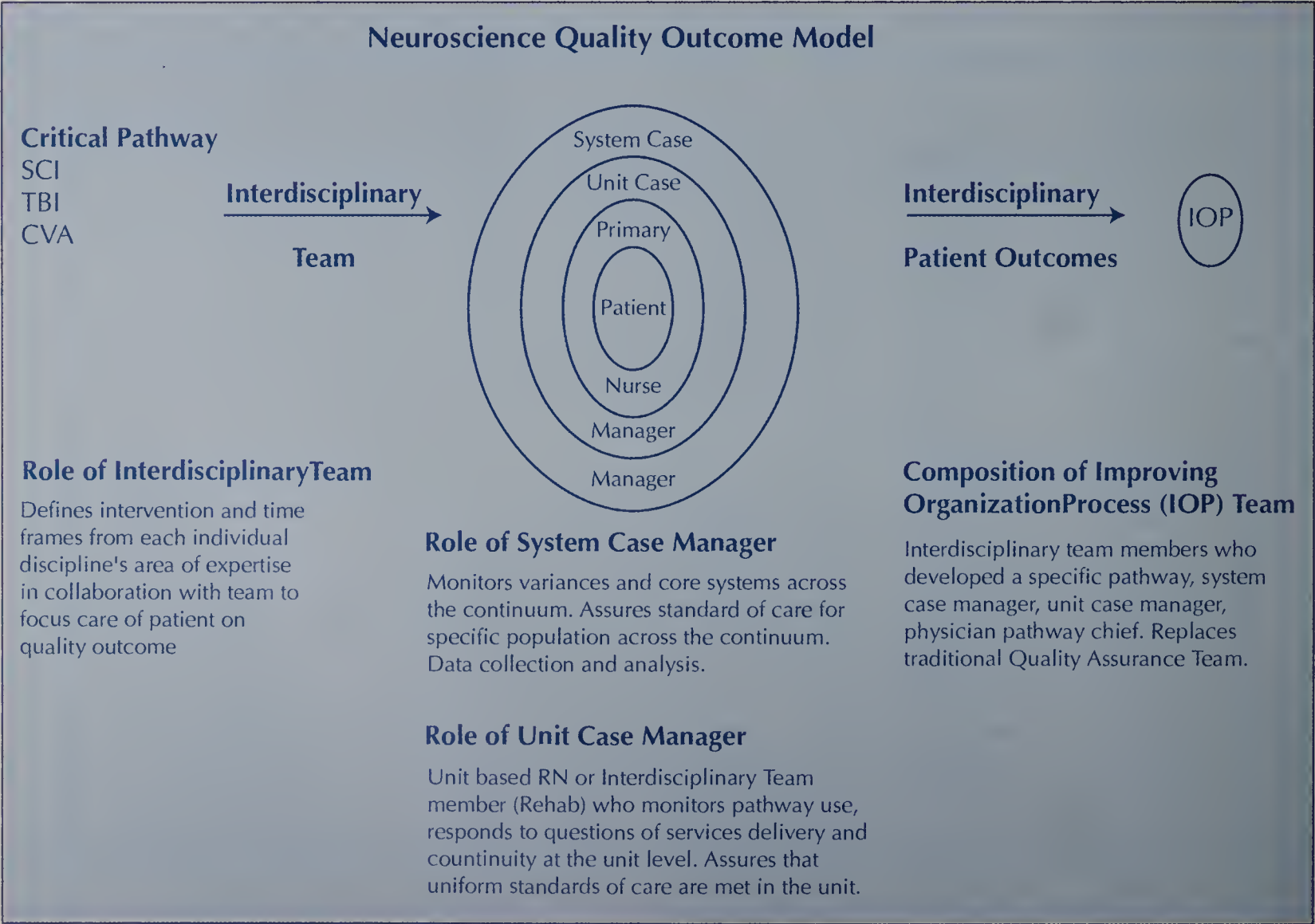
A second benefit of the development process included an improved interdisciplinary approach to the care of the patient. Before the team formed to develop the pathway, the practice of the acute care team was multidisciplinary. Rehabilitation practiced in interdisciplinary care was highly proficient, but we needed to strengthen the links within the continuum. The process of the development of the pathway demonstrated to the acute team the difference

in interdisciplinary and multidisciplinary practice. For the rehabilitation team the process improved their interdisciplinary performance.

Finally, and perhaps most importantly, a bond developed between the members of the team. We learned respect for each other as clinicians as we worked together to meet a common goal, a goal that often seemed as if it would not be met. The end result of the bonding that occurred was a more cohesive interdisciplinary team that could communicate more effectively regarding SCI patients across the entire continuum of care.

Outgrowth of the Pathway

As a result of the original development of the spinal cord injury critical pathway, several important projects have emerged.



It is the process of team collaboration that ultimately produces quality outcomes and strong links in the continuum of care.

First and foremost, the pilot data from the original pathway led to the development of a research project in the Model Systems for Spinal Cord Injury. The objectives include determining the influence of case management and critical pathways on positive outcomes for SCI patients. These outcomes, in addition to length of stay and cost, also include looking at the influence of interventions on reducing complications and promoting increased function.

Another important objective of the project will be to determine what interventions are critical and what the timing of those interventions should be in promoting positive outcomes. For example, we plan to examine the relationship between the timing of interventions, such as physical therapy/occupational therapy, and outcomes, such as length of stay and functional improvements. Other significant areas of examination will include the relationship between substance abuse history, level and type of pain, degree of spirituality, and the afore mentioned outcome measures. As noted earlier, no literature exists that suggests "critical" interventions and the timing of those interventions as they relate to positive outcomes for patients with spinal cord injury.

Along with the Model Systems research project, a second research study has been developed by the nursing staff

of the Neuroscience Intensive Care Unit that will involve a qualitative approach to exploring the experience of SCI patients in intensive care. This data then can be used to enhance the acute phase of care for patients with SCI.


Finally, a continuous quality improvement project has arisen from the focus on SCI in the institution. The neuroscience quality improvement group has embarked on a project to elucidate the factors that contribute to the breakdown of skin in patients with SCI. The group is exploring nutrition and length of time on backboards as possible variables in the skin breakdown problem.

Conclusions

Critical pathways are tools to achieve patient or programmatic outcomes. They are not an end in themselves, and attempts to develop pathways without interdisciplinary collaboration and a programmatic vision will not meet with complete success. It is the process of team collaboration that ultimately produces quality outcomes and strong links in the continuum of care.

Case management is critical to the success of pathways in populations that are complex, multivariant, and have high resource utilization. By guiding the process of pathway implementation and variance analysis, the case manager can assure value to the SCI patient throughout the continuum of care.

Value can also be provided to other customers of the organization via the use of pathway data. Through variance analysis the case manager can focus the team on outcomes of their practice and on methods to enhance those outcomes. This same data can be used to provide managed care organizations benchmarking information on the value of the institution's services and can simultaneously provide hospital administration additional opportunities for service improvement. It is with the service improvement vision fully in focus that case management/critical pathways systems become powerful tools to link clinicians, healthcare organizations, and payors in

providing quality services to persons with spinal cord injury. 

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Assistive Devices: Empowerment Issues



Prone Cart

Irma Fiedler, Ph.D.

Assistive technology (AT) began with the first individual who used a stick as a means of augmenting mobility. The present state of the art of assistive technology, with its focus on robotics and virtual reality, must represent the fulfillment of science fiction for persons born as recently as the end of World War II.

Assistive technology, in its truest sense, becomes not just an enhancer for those with a spinal cord injury, but a lifeline. It can permit individuals to be environmentally, vocationally, and emotionally empowered in a manner not thought possible during the past decade.

An assistive technology device has been defined as "any item, piece of equipment, or product system, whether acquired commercially off the shelf,

modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities."¹ Internationally, those devices used as a means of assistance are conceptually differentiated as tools and appliances. Those devices that augment or assist a function are described as tools, while devices that replace a function are conceptualized as appliances. The term rehabilitation technology (RT) formalizes this taxonomy.²

It would appear that a comprehensive discussion of AT must include the following: the physiological and functional assessment/integration, the resource evaluation-possible AT options, the acceptance challenge, the training model, and the financial support feasibility. Unfortunately, particularly in a precarious healthcare environment, the financial support issues may take precedence

over earlier essential therapeutic steps. According to O'Day and Corcoran,³ concepts such as durable medical equipment (DME) and the classical definition of what is termed "medically necessary" may not support the reality of what people with disabilities need to be independent. The authors, in their comprehensive analysis of funding and support problems in AT, focus on the highly involved process of accessing funds to support the appropriate DME or assistive devices. There appears to be an absence of appropriate centralized resource systems. In addition, elements of fraud and abuse are not uncommon and inconsistencies exist within and between programs. Unfortunately, the ideal assistive technology, appropriately matched and accepted by the individual with a spinal cord injury, may not be feasible within the present funding guidelines. Accommodating what is feasible with what is necessary is truly a challenge for those interested in maximum empowerment.

As defined by Platts, et al.,⁴ four areas can be delineated in assistive devices for high spinal cord lesions: mobility, manipulation, communication, and control of the environment. The authors stress the need for assistive devices even in those individuals with full-time caretakers. Since a device can free the carer for other duties, lighten the burden, and increase morale in the individual with a spinal cord injury, the most cost-effective approach would be to permit the support of maximum assistive technology.

Physiological and Functional Needs Assessment/Integration

Inpatient evaluation of functional needs for the individual with a spinal cord injury must include extreme sensitivity to that person's fragile state following injury. Previous bias and prejudice which the individual may hold may seriously interfere with the willingness and acceptance level for assistive technology. Empowering the individual at this early stage will permit decisions to be made *with* the patient rather than *for* the patient. This approach and sensitivity will assist in developing the indi-

vidual as an enabler and self-advocate for future needs assessment. Dialogue focusing on the various needs and available alternatives at the conceptual level will enable the therapist, usually an occupational therapist, to elicit any preconceived fears or negative attitudes toward a particular device or means of augmentation. Welch et al.,⁵ stressed the need for the assessment of a patient's lifestyle, skills, and desires before decisions regarding AT are made, since a decrease in the use of earlier prescribed equipment upon community entry appears prevalent.

In a discussion of wheelchair adaptation, Bates et al.,⁶ found a dissonance between the goals of the therapist and those of the patient. This conflicting status was evidenced by attitudinal shifts on the part of the patient, ranging from resistance to neutrality and, in some cases, detente. Studies have reported the lack of use of frequently prescribed assistive devices, such as splints and adaptive feeding and grooming equipment, for reasons other than attitudinal preference. One study,⁷ cited the lengthy time required for appropriate placement of the device, while another study⁸ found that improved physical function and alternative solutions were found, thereby diminishing usage of the device. More expensive devices, such as orthoses and ball bearing feeders, were devices which were retained most often. Perhaps more time and research is involved in the selection and fitting of an appliance, thereby accounting for its long-term retention.

Resource Evaluation/Availability

The pairing of an assistive device with the user is, in a sense, almost a marriage. In the ideal situation, the assistive technology will fuse with the individual, generating a harmony of functionality. Personal adaptation, readily available and financially feasible, can be as simple as a splint or the modification of a trombone trigger using a ring instead of the usual trigger⁹ operated by the thumb.

The various options in the field of AT are presently awe inspiring. From

Table 1 Assistive Technology: Common Examples	
Mobility Aids walking canes crutches, walkers wheelchairs electric wheelchairs wheelchair cushions adapted seating systems car hand controls portable ramps wheelchair lifts for vans	Self-Help Devices reachers one-handed can openers adapted utensils button aids
Sensory white canes eyeglasses low-vision aids Braille writers hearing aids TDD's speech synthesizers	Home Equipment hospital beds alternating pressure mattresses lifters and transfer aids commodes, bedpans tub seats, shower chairs grab bars
Prosthetics artificial legs powered arms and hands breast prosthesis eye prosthesis ear and nose prosthesis dentures	Home Modifications lowered counters widened doors ramps wheelchair lifts stair lifts environmental control systems railings
Orthotics hernia appliance (truss) hand splints back braces body jackets leg braces shoe orthotics orthopedic shoes elastic joint supports ostomy appliances	Implantable Devices defibrillators artificial hip & knee joints breast implants insulin pumps pacemakers
	Miscellaneous TENS (transcutaneous electric nerve stimulators) home cervical traction edema compression sleeves oxygen generators

the classic mouthstick to virtual reality, the individual has a smorgasbord of alternatives, limited only by imagination and funding. O'Day and Corcoran³ list the following display as representative of the myriad of available options.

DME and the needs of individuals with SCI is discussed, in depth, in a booklet developed by the American Spinal Injury Association.¹⁰ Geared to the needs of the consumers, it provides providers and payors a resource to determine if equipment is feasible, realistic, and appropriate. The use of a

comprehensive guide cannot be overstated in this complex environment of healthcare.

A state-of-the-art compendium on the use of assistive technology is available from the American Medical Association.¹¹

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This resource includes extensive evaluation, referral, and prescription information and would be a definite asset in managing an assistive technology program.

Symington¹² described the recent innovations in assistive technology as a "megatrend in rehabilitation." An example of this megatrend can be found in functional electrical stimulation (FES),¹³ a surface electrical means of potentially activating paralyzed limbs. Robotics, ranging from sensory feedback with a virtual headstick¹⁴ to a gesture-programmed, multimodal rehabilitation robot,⁴ offer an unimaginable future. Seamone and Schmeisser,¹⁵ in a comprehensive discussion of micro-computer technology, discuss the essential requirements to fully assess the needs of quadriplegic patients with SCI. The use of a single, multipurpose device, such as a robot, requires discrete clinical evaluation. The authors evaluated the needs of patients and determined that items such as telephone usage, self-feeding, and typewriter usage (to include insertion and removal of paper) could be met by a multipurpose robot arm/worktable system. Robotics offers a window into a future of accessibility for individuals with SCI.

One example of the use of new technology, using new metals and including the assessment of a patient's individual needs and desires, is the design of a new prone cart.¹⁶ As part of a National Institute on Disability and Rehabilitation Research (NIDRR) sponsored model systems grant, prototypes of a new, cost-effective, lightweight prone cart are now being tested by patients. The cart (Figure 1) allows the user to rest in an angled position, whereby he/she is better able to access the environment. Relieving back pressure, the altered position and torso support permits the adjustment of the front angles to achieve comfort. The torso support permits the free use of the individual's hands, thereby increasing functionality. The functional characteristics of the prone cart were developed as the result of discussions with patients and caregivers, individuals most aware of the criteria for need fulfill-

ment. The portable aspects of the prone cart permit an environmental accessibility heretofore not available; the cart can be loaded into a van, thereby accessing the outside environment, i.e., shopping malls, restaurants, theatres.

Utilizing available methods to recreate objects of everyday use is the major focus of design research.

The prone cart, developed by the Veterans Administration and refined under the NIDRR grant, is heavily influenced by recent adaptations in bicycle models. The large diameter, thin wall tubing is used to save weight and add an aesthetic balance to the vehicle. A type of bicycle model adaptation, the aerospace material "carbon fiber" recently appeared in wheelchair frames, having appeared for the first time in a bicycle frame no more than 6 years ago. The futuristic appearance of the prone cart addresses not only the cart's performance but also the image the vehicle projects, an important component in acceptance. As stated by the designer, translating performance technology into objects regarded as utilitarian, redefines the object, peoples' opinions/perceptions, and the attitudes of those who use the device. Changing an attitude from one of complacent utility to involved performance is significant to the user and to those who create the objects used.

Utilizing available methods to recreate objects of everyday use is the major focus of design research. The success of this new prone cart is simply restating an old object with new materials and perceptions. The prone cart, with its lightweight materials and aesthetically


appealing color (hot red), appeals to the consumer and the provider. It was produced when a need was expressed and it was designed with input from the consumer, the designer, and the manufacturer. The cart will be environmentally tested before actual factory production takes place (Figure 1).

The Future: Research and Development

Training models, technical assistance, and outreach resource projects are two recent areas of research and development. Sponsored by the U.S. Department of Education, project TRANS-TRAIN¹⁷ is a transdisciplinary project to develop courses and guide design projects with internships, focusing on the development and use of assistive technology. This program is an attempt to formalize the training process by establishing a certificate program in assistive technology under the auspices of the Department of Special Education and Rehabilitation, San Diego State University, to complement an existing certificate program in supported employment and transition. Projects recently developed as part of this training program include: customized work stations for computer use; a custom-made vest harness for transportation of electronic devices; remote-controlled, self-locking, and unlocking automatic front door; an adapted lunch box; and telephone receiver modification. The development of standardized curricula and the formalization of education mark significant gains in assuring that assistive technology services will be consumer-driven and expertly provided.

The development of a resource for rehabilitation robotics¹⁸ represents significant progress in integrating services in assistive technology. The resource, funded by NIDRR, numerous research programs, and the A.I. DuPont Institute, is responding to the national need for dissemination of resources on robotic advancement. Projects to be developed in the resource center include an annual videotape, World Wide Web server, and varied newsletters, conferences, and communications.

Virtual reality is a world unto itself. It changes assistive technology from a tool, appliance, or device to an environmental assistance technology. Life satisfaction in the past for the individual with a spinal cord injury was dependent upon AT, carer limitations, and independent functioning. Virtual reality permits an individual who is disabled to have experiences which do not require physical functioning. Now one can ski, fly, and run without the necessary physiological supports, a world apart from restrictions. Virtual reality may truly change life satisfaction, goals, and achievements for an individual with a spinal cord injury.

The art of assistive technology is moving toward the establishment of a science of assistive technology. Developing better methods of assessing needs is as relevant as the development of sophisticated devices. It is the appropriate marriage of the consumer with the available resources which will ultimately result in consumer satisfaction and usage. 

EDITOR'S NOTE: Information on durable medical equipment (DME) for the patient with SCI is available from the American Spinal Injury Association at (404) 355-9772. For readers wishing information on the state-of-the-art compendium on the use of assistive technology, the telephone number for the American Medical Association is (312) 464-5095.

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NEW PUBLICATIONS AND FILMS

The Performance of Healing.

Carol Laderman and Marina Rosenman, editors. Routledge, 7625 Empire Dr., Florence, KY 41042. Softcover, 330 pages. \$18.95.

This text is a collection of essays by anthropologists covering a wide range of medical, holistic, and religious aspects of healing and death. The contributors broaden the field of medical anthropology by demonstrating that healing involves the senses in treatments whose efficacy depends in part on dramatic performance.

Music, movement, and dialogue; comedy and poetry; audience, players, and props—all constitute the performance of healing. If healing is to be effective, the patient's body and mind must be engaged through the sensory impact of dramatic media, the articles show. Curing is not just about "making people well," but also forms a crucial means of reproducing relations of power. A performance directed toward a particular individual might also heal a traumatized social group, expanding the definition of "cure" from its narrow sense of restoring a victim to health to the larger goal of restoring social relations.

Understanding Rheumatoid Arthritis.

Stanton Newman, Ray Fitzpatrick, Tracey A. Revenson, Suzanne Skevington, and Gareth Williams. Routledge, 7625 Empire Dr., Florence, KY 41042. Softcover, 231 pages. \$18.95.

Rheumatoid arthritis (RA) is a major cause of disability affecting about 1 percent of the population. Although much effort has been expended on research into the causes of RA, little progress has been made towards a cure. The focus of treatment is on reducing the

disabling consequences of disease and controlling the symptoms.

This text examines the nature of RA and its treatment, individuals' experience of RA, and its symptoms of pain and stiffness. An overall understanding of the impact of RA on quality of life is presented as well as the role of health-care professionals and encounters with the doctor, all of which influence the individual's behavior towards his/her rheumatoid arthritis.

Worlds of Illness.

Alan Radley, editor. Routledge, 7625 Empire Dr., Florence, KY 41042. Softcover, 205 pages. \$17.95.

The articles in this book examine people's experience of illness and their understanding of what it means to be healthy. The authors, who are from a variety of fields, use an approach which stresses the biographical and cultural contexts in which illness arises and is borne by individuals and those who care for them. It emphasizes the need to understand illness in terms of the patient's own interpretation, its onset, the course of its progress, and the potential of the treatment for the condition.

Pastoral Care of the Mentally Disabled. Advancing Care of the Whole Person.

Sally K. Severino, M.D., The Reverend Richard Liew, Ph.D., editors. The Haworth Medical Press, 10 Alice Street, Binghamton, NY 13904-1580. Hardcover, 116 pages. \$14.95.

Pastoral Care of the Mentally Disabled addresses the perceived roles of clergy and physicians for healing the whole person, stressing that this best occurs when medicine and ministry are

yoked. The contributing authors establish new tasks that must be developed to meet the needs of the whole person in the process of mending minds (medicine) and mending souls (ministry).

The 16 contributors encourage a partnership toward evaluating and treating patients with mental illness with chapters on such topics as the role of faith in mental healing; the role of mental health in spiritual growth; personal history of Anton Boison, a leader in the pastoral care movement who suffered from mental illness; practical application of concepts to a clinical case; and a partnership model for tending persons who are mentally disabled.

Fibromyalgia, Chronic Fatigue Syndrome, and Repetitive Strain Injury. Current Concepts in Diagnosis, Management, Disability, and Health Economics.

Andrew Chalmers, M.D., Geoffrey Owen Littlejohn, M.D., Irving Salit, M.D., and Frederick Wolfe, M.D., editors. The Haworth Medical Press, 10 Alice Street, Binghamton, NY 13904-1580. Hardcover, 182 pages. \$24.95.

A summary of information from a conference on chronic fatigue syndrome (CFS), fibromyalgia syndrome (FS), and related disorders held in Vancouver, Canada, in 1994, this collection of writings emphasizes disability and compensation. The conference was designed to address etiology, pathogenesis, clinical features, treatment, disability, medico-legal issues and cost containment. The program agenda was issue driven rather than condition based. The papers were presented in a manner which allowed delegates and speakers to see the overlap and differences between these conditions.

Occupational and Physical Therapy in Educational Environments.

Irene R. McEwen, editor. *The Haworth Medical Press, 10 Alice Street, Binghamton, NY 13904-1580. Hardcover, 110 pages. \$29.95.*

Covers the major issues involved in providing lawful, team-oriented, and effective occupational and physical therapy services for students with disabilities in public schools. For those involved with students with disabilities, this book helps them make sound decisions about services that will make a meaningful difference in the lives of these children.

Since the 1975 enactment of Public Law 94-142, which mandated that occupational and physical therapy be provided "as may be required by a handicapped child to benefit from special education," this required link between therapy and education has continued to lead to confusion and controversy about which students should receive therapy in school and what types of services should be provided. The purpose of this text is to clarify the major issues surrounding occupational and physical therapy in public schools and to provide a framework for delivery of team and family oriented services that meet individual needs of students with disabilities.

Mental Health in a Multi-ethnic Society. A Multi-disciplinary Handbook.

Suman Fernando, editor. *Routledge, 7625 Empire Dr., Florence, KY 41042. Softcover, 235 pages. \$18.95.*

As services in the community continue to replace institution-based care there is an increasing need for professionals from medical, social work, clinical psychology, nursing, and other backgrounds to address the diverse needs of a multi-ethnic society using a common frame of reference. Those who provide mental health services must now face up to challenges from service users and strive for a closer, more effective working relationship with voluntary organizations. This book attempts to address all these issues. It offers an approach to the meaning of mental health

and suggests constructive and imaginative ways of providing care for people with mental health problems.

Contributions from a multi-ethnic team of professionals are organized in three parts: "Current setting" describes the background to contemporary mental health services, the legal framework, and the role of the voluntary sector and examines the experience of black people. "Confronting issues" considers practical problems in delivering services to a multi-ethnic society and offers some innovative approaches. The final part, "Seeking change," draws together the various issues in order to indicate a way forward, with suggestions for change on both a practical and theoretical level.

Intended primarily as a handbook for practitioners working in the mental health field, it is also suitable for multi-disciplinary, basic, and in-service post-graduate trainings in a variety of professions, including social work, psychology, psychiatry, and nursing.

Directory of College Facilities and Services for People with Disabilities. Fourth Edition.

Oryx Press, 4041 North Central Ave., Suite 700, Phoenix, AZ 85012-3397. *Softcover, 392 pages. \$125. Also available in a 8 1/2 by 11 inch case binding for \$115 in North America. Call toll free 1-800-279-6799 or fax toll free 1-800-279-4663. Outside the U.S. call 602-265-2651 or fax 602-265-6250. Please add 10 percent for shipping and handling, plus sales tax in Arizona and Canada.*

Disabled college-bound students can quickly find current information about university services and programs in the fourth edition of the *Directory of College Facilities and Services for People with Disabilities*. Completely revised and updated since the passage of the Americans with Disabilities Act in 1990, the directory includes more than 1,500 colleges and universities in the U.S., Puerto Rico, Guam, and Canada.

Institutions are listed alphabetically in the directory by country and then by state or province. Each entry provides a profile of the institution, the campus and facilities, and the services provided.

The institution description includes information on the type of college, degree(s) granted, number of students with disabilities enrolled, and disability categories represented. Categories include visually impaired or blind, hearing impaired or deaf, speech/language disordered, orthopedically or mobility impaired, learning disabled, and developmentally disabled.

The campus and facilities category provides information about residential facilities, including the number of specially equipped dormitory spaces for students with disabilities and the manageability of the physical terrain and layout of the campus for mobility impaired persons. Accessibility of various facilities, including classrooms, labs, studios, dorms, dining facilities, gyms, student unions, libraries, and other buildings, are also listed.

The services category gives specific information about special services provided for students with disabilities, including special financial aid programs, disabled student resource centers, individualized curriculum tutoring, registration assistance, aids for library research, transportation assistance, reader service, taped books, special computers, closed-circuit television, note takers, interpreters, TTY/TTD access, and visible warning systems. Fees for these services are also listed.

The Fibromyalgia Syndrome. Current Research Directions in Epidemiology, Pathogenesis, and Treatment.

Stanley R. Pillemer, M.D., editor. *The Haworth Medical Press, 10 Alice Street, Binghamton, NY 13904-1580. Hardcover, 184 pages. \$29.95.*

The *Fibromyalgia Syndrome* summarizes major advances in the understanding of fibromyalgia and helps increase readers' knowledge of the disorder. Fibromyalgia is not an uncommon disorder, and can be a frustrating problem for patients and physicians alike. In this reference, leading experts in the field of fibromyalgia research provide up-to-date information on fibromyalgia and offer suggestions for future research.

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AMERICAN Spring 1997 REHABILITATION



**Spinal Cord
Injury**
Part 3 of 3

Vocational Rehabilitation's Continuing Commitment to Services for Individuals with Spinal Cord Injury



Fredric K. Schroeder

This issue of *American Rehabilitation* concludes a three-part series on the subject of spinal cord injury, with the following topics covered: "Rural Healthcare Initiatives," "Independent Living," "Community Integration," "Prevention of Spinal Cord Injury," "Aging with SCI," and "Sexuality."

Today the state-federal vocational rehabilitation program provides services to many individuals with spinal cord injuries. As an example, in 1994 (1995 data are similar), approximately 13,000 individuals with spinal cord injury were served by the vocational rehabilitation system. Of these, over 5,500 were successfully rehabilitated. When entering vocational rehabilitation, 695 were competitively employed, 10 were in sheltered employment, 59 were self-employed, 72 were homemakers, 10 were unpaid family workers, and 4,337 were not working. Whereas, at closure from the VR system 4,808 of these same individuals were competitively employed, 39 were in sheltered employment, 333 were self-employed, 312 were


homemakers, and 25 were unpaid family workers (there are data missing for 1 individual). During the rehabilitation process, 1,549 received college training, 1,538 received business training, 333 received on-the-job training, 2,048 received placement, and 2,293 received other services. People with spinal cord injury, when compared to all other individuals who are considered rehabilitated tend to be older at application (35.7 years of age vs. 34.4 years of age) and closure (38.1 years of age vs. 36.3 years of age), longer in service (29.2 months vs. 23.4 months), more costly to rehabilitate (\$5,162 vs. \$3,111) and more educated (11.74 years vs. 11.46 years).

Individuals with spinal cord injuries have dramatically benefitted from the rapid advances in computer related and other technologies. Electrically powered wheelchairs and devices permitting control of electronic devices at home are commonplace. Manual wheelchairs have advanced from heavy clumsy devices to racing vehicles. Other advances have been made in pain management, biofeedback, and functional electronic stimulation.

Recently, modern medicine has begun exploring the possibility of finding a cure for spinal cord injury. This early research offers the prospect of looking beyond prevention to the possibility of reversing the consequences of spinal cord injury.

One of the most pressing issues for individuals with spinal cord injuries is a national comprehensive approach to the provision of personal assistance services. When such services become as commonplace as ramps and electric wheelchairs, individuals with spinal cord injuries will truly have full access to all the benefits that this great country offers its citizens.

The combination of community supports, increased availability of technology, civil rights, and access to education and employment provides a rich pallet for rehabilitation counselors to assist individuals with spinal cord injuries in obtaining the necessary skills, training, and encouragement to obtain employment.

I am hopeful that this series on spinal cord injury will serve as an important resource on the subject of spinal cord injury for many years to come. 

AMERICAN REHABILITATION

Volume 23, Number 1

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Cover Photo: Russ Holt, a counselor for the Endependence Center of Northern Virginia (ECNV), buys a ticket at the Arlington, VA, movie theater he often frequents, sometimes alone and often with participants of ECVN. (photo by Frank Romano)

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Rural Healthcare Initiatives in Spinal Cord Injury

This article provides an overview of the barriers to healthcare and the subsequent problems faced by individuals with SCI in rural America. A sampling of several unique and innovative programs designed to facilitate access to high quality healthcare and promote productive, independent rural living is then provided. This review is not exhaustive in its coverage of healthcare initiatives but is intended to be representative of existing programs.

Kristofer Hagglund, Ph.D.
Daniel L. Clay, Ph.D.

For a variety of reasons, people with spinal cord injuries (SCI) in rural areas have been underserved by the healthcare system.

Not only are there fewer healthcare providers—particularly providers trained in rehabilitation or spinal cord injury—family practitioners and other generalists in rural areas often have less experience with medical management of spinal cord injuries than do their urban counterparts; this lack of experience is due to the fact that people with SCI previously remained close to tertiary care centers to receive essential medical care following injury.

Similarly, behavioral healthcare has been fragmented and inconsistent. Few mental or behavioral health providers in rural areas are familiar with the unique challenges of spinal cord injury. In failing to recognize these challenges during diagnostic evaluation and treatment planning, persons with SCI have been treated ineffectively and/or inappropriately.

Other impediments to quality healthcare include transportation limitations, physical/architectural barriers, attitudinal restraints, and lack of knowledge about the specific needs of people with SCI in rural America. In spite of these obstacles, individuals with SCI and other disabilities are exercising their right to choose where to live and, increasingly, they are choosing rural communities.

Accurate estimates of the number of rural dwellers with spinal cord injury are not available, but perhaps as many as 13 million rural Americans have permanent disability of some form. The Breaking New Ground Resource Center (BNGRC) estimates that there are approximately 4,500-6,500 farm/ranch families with a member with SCI.¹ Although the healthcare delivery system has been slow to respond to the unique needs of this population, programs that may improve the quantity and quality of healthcare for persons with SCI in rural areas are being developed. These programs are not typically specific to the needs of persons with SCI, but are usually designed for individuals with a variety of disabilities.

Most rural healthcare initiatives operate on a state and/or local level (sometimes with financial support from federal agencies) and the reader is encouraged to contact local resources (e.g., Center for Independent Living, library, county commission) to identify available rural healthcare programs.

Barriers to Quality Care in Rural America

The major healthcare concern for persons with SCI in rural areas is access to high quality, least restrictive care. Lack of access to knowledgeable providers and adequately staffed and equipped facilities increases the potential for unnecessarily compromised quality of life, including reductions in independent functioning, productivity, and life satisfaction.

The obstacles to healthcare access in rural areas have been well documented.² Local, state, and federal government agencies have begun to focus on overcoming these barriers to provide more comprehensive and effective services.³ This task has been enormous, however, given the disproportionate number of rural people who are poor⁴ and the lack of financial resources in rural areas. The difficulties the general population experiences in accessing quality healthcare are compounded by the challenges associated with a disability. A previous needs assessment in rural Arkansas, for example, revealed the most significant problems encountered by persons with disabilities included economic limitations, unemployment and underemployment, restricted transportation, and healthcare shortages.⁵ A survey by the Breaking New Ground Resource Center revealed that more than 30 percent of farmers and ranchers with SCI purchased and obtained service on their wheelchairs and other mobility aids more than 100 miles away from their homes. Additionally, approximately 34 percent lived more than 51 miles from rehabilitation services.¹

Passage of the Americans with Disabilities Act (ADA) in 1990 is facilitating removal of barriers to healthcare, employment, transportation, and other

important domains of life, but application of ADA to rural areas is slow and will take many more years before full compliance is obtained. There is sparse empirical data about the extent or impact of physical, educational, financial, attitudinal, and other barriers for persons with SCI in rural America. Nevertheless, anyone who lives in or travels to small towns in rural America will see that wheelchair accessible housing, shopping, recreational facilities, and public facilities are uncommon. The BNGRC study found that farmers and ranchers with spinal cord injuries were frequently unable to participate in previously enjoyed social and community activities, such as church or agricultural organizations, because facilities were physically inaccessible.¹ Furthermore, the continuing economic crisis in rural America has left many main streets with empty buildings. With the migration to urban centers, there is an increasing scarcity of resources for implementing changes to accommodate persons with SCI.

The limited available information suggests that the recognized barriers associated with rural areas have been shown to be very costly both to the person with SCI and the health delivery system. For example, delayed discharge from acute rehabilitation following SCI due to the lack of wheelchair accessible housing is costly to the individual and the rehabilitation hospital.⁶ As many as 10 percent of all patients admitted for SCI rehabilitation have been found to be delayed in their discharge due to a lack of appropriate settings for discharge. The average costs associated with these delays was \$29,280. The cost for one patient who remained in the hospital 210 days after being ready for discharge was \$102,480.⁶

This problem was experienced firsthand recently by Dr. Clay (one of the authors of this article) at his rehabilitation center. A 24-year-old patient with C6 tetraplegia was ready for discharge for 2 months before actual discharge because facilities were not available that could provide the level of skilled care needed. As with many rural people with SCI, this patient did not have

adequate access to reasonably-priced health insurance and, therefore, was underinsured. At a per diem cost of \$987, this patient cost the hospital \$59,220. There have been a number of studies evaluating the costs of care⁷ and the effects of insurance coverage, payment, and utilization of monetary resources on psychosocial outcome in SCI.⁸ However, to date there are no studies that look specifically at barriers to community reintegration and access to care specifically in rural areas related to costs of healthcare.

Research on outcome of persons with SCI is increasingly focusing on subjective well-being, or life satisfaction, as well as community reintegration.

Research on outcome of persons with SCI is increasingly focusing on subjective well-being, or life satisfaction, as well as community reintegration. Life satisfaction has been recently identified as an important determinant of outcome for persons with disabilities.⁹ Studies have found that persons with chronic physical impairments have reported lower life satisfaction scores than people in the general population,^{10,11} but life satisfaction has been shown to be unrelated to the severity of disability.¹⁰ Nosek and colleagues¹² examined the relationship between life satisfaction and self-appraised adequacy of personal assistance in 45 people with disabilities and found evidence suggesting that the adequacy of personal assistance may have a strong influence on life satisfaction. If the quality of care provided in rural areas is poorer due to lack of available caregivers and re-

sources, life satisfaction, independence, and productivity will be lower also.

Overall, the problems of poor access to high quality care encountered by persons with SCI in rural communities are similar to those of persons without significant disabilities but are compounded by physical, attitudinal, educational, and economic barriers. Unavailability of quality care appears to have a significant negative impact on the quality of life for persons with SCI in rural America, although there is inadequate knowledge of the extent and nature of the barriers unique to SCI in rural areas. Nevertheless, advocates, clinicians, and researchers have heeded an unwritten mandate to develop innovative programs to meet the health-care needs of this population.

Model Spinal Cord Injury Systems

The 18 Model Spinal Cord Injury Systems, funded by the National Institute on Disability and Rehabilitation Research, are increasingly turning their focus to persons with SCI who have been underserved, including those in rural areas. Two collaborative demonstration and research projects involving several model systems and affiliated Centers for Independent Living (CIL's) are examples of initiatives that may prove useful to meeting the previously unmet needs of rural dwellers with SCI. The Mount Sinai Model Spinal Cord Injury System is leading a project to establish a national network of advocacy groups to focus on teaching individuals with SCI how to participate in the development of clinical programs, influence the direction and scope of research, and direct policy de-

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velopment. The University of Michigan Model Spinal Cord Injury System is directing a project involving CIL's to enhance community integration by including independent living personnel during acute rehabilitation to help shift the focus from medical interventions and physical restoration to independent living following discharge. Further collaboration between the model systems and other tertiary care centers with CIL's is needed to enhance the transition from medical care to independent, productive living and to enhance consumers' advocacy skills. Through CIL's and national consumer organizations, consumers should become major players in state and federal healthcare policy, including guiding research, developing clinical endeavors, and advocating for legislation to serve rural areas.

Missouri Model Spinal Cord Injury System

The mission of the Missouri Model Spinal Cord Injury System (MOMSCIS) focuses on improving access to high quality rehabilitation services by supporting integrated comprehensive community-based systems of healthcare delivery. Increasing access is intertwined with identifying those populations that have been underserved. Through focus groups and discussions with community agencies (including a CIL), the MOMSCIS identified the underserved in Missouri to be primarily women, minorities, and those persons living in rural areas. Following the concept of "rehabilitation without walls," two projects were initiated to redesign the manner in which healthcare is provided to individuals in rural Missouri. The first involves a physiatrist-clinical nurse specialist team that travels on a quarterly basis to rural CIL's to provide education on SCI to the center staff, local physicians, and other local healthcare providers. Also, these CIL's provide space for a "clinic" in which persons with SCI can be seen by the physiatrist and the nurse practitioner. Setting up clinics in churches, CIL's, local organization buildings, and

other nontraditional settings is one way in which needed care can reach those in rural areas.

The second initiative is a collaborative project to establish a managed health delivery system for persons with disabilities receiving Medicaid benefits in central Missouri. Under the technical guidance of the Medicaid Working Group, the University of Missouri Health Sciences Center; the State of Missouri Department of Social Services, Division of Medical Services; and a licensed health maintenance organization, "Healthcare Options Plus," will soon be enrolling voluntary participants in a managed healthcare delivery model in which physiatrists will team with nurse practitioners and internists to provide primary healthcare for people with disabilities, including SCI. A focus of this program is providing outreach services to patients who are not able to travel for medical services and/or have not been able to establish a relationship with a knowledgeable community-based general practitioner. The outreach services, designed to prevent costly medical complications and improve quality of life for patients, will include healthcare professionals visiting patients in their homes to provide preventive and primary care. An additional aspect of the program design is the complete programmatic and financial integration of behavioral health services, including rehabilitation psychologists as primary mental health care providers. Finally, the local CIL is working with the other collaborators to teach consumers to hire, contract, and manage their own personal care assistants, which will be a covered service in Healthcare Options Plus.

AgrAbility Project

The AgrAbility Project was created with the 1990 farm bill to enable individuals with disabilities to resume their careers in agriculture.¹³ This program, directed by the U.S. Department of Agriculture (USDA) Cooperative State Education, Research and Extension Service, in cooperation with the National Easter Seal Society and Purdue University's Breaking New Ground Re-

source Center, provides expertise and service to farmers, ranchers, and agricultural workers who have been injured and who might not return to work because of the lack of knowledge about the interaction between rural and disability needs.

AgrAbility currently operates in 22 states and, although its consumers include the 500,000 farmers, ranchers, and agricultural workers with varying disabilities, persons with spinal cord injury comprise one of the principal consumer groups.

AgrAbility focuses on providing education and assistance in the form of expert advice on modification of equipment and/or methods, coordinating resources, and promoting agricultural safety and preventing secondary injury. The BNGRC also provides technical and onsite assistance for persons with disabilities and conducts research and disseminates information addressing disability and agriculture.

Telemedicine

Telemedicine¹ is exploding across the nation and may prove to be a valuable tool for patients and providers in rural areas; its projects are in use or are being developed in at least 40 states with hundreds of millions of federal, state, and private dollars funding new initiatives. Although it involves a number of technologies, telemedicine usually refers to two-way interactive television providing long-distance specialty medical consultation (Perednia & Allen, 1995), which clearly makes it a promising form of health services delivery for persons with SCI, especially those who live in rural areas. Other common uses for this technology include education and administrative functions. As described by Perednia and Allen,¹⁴ "Telemedicine can be useful for situations in which (1) physical barriers prevent the ready transfer of information between patients and healthcare providers and (2) the availability of information is key to proper medical management." Transportation difficulties and long distances between knowledgeable providers and consumers are common physical barriers.

ers whose negative impact on the lives of persons with SCI in rural areas should not be underestimated. Clinicians who serve remote areas note that patients often aggravate skin breakdown by traveling from home to the clinic to be seen, resulting in more costly and cumbersome treatment, including hospitalization. Telemedicine that utilizes "real-time" interactive video can efficiently bring much needed access to high quality medical services. In general, healthcare providers hope to use telemedicine to reduce the economic barriers and medical complications of providing rural healthcare.

In most rural settings, specialty healthcare services are unavailable to the community because the costs of staffing and infrastructure are prohibitive.¹⁴ Psychiatrists and other healthcare providers with specialized knowledge of SCI and its treatment can use telemedicine to provide services to persons who would otherwise have to travel great distances or only be seen by providers without specialty training. Increased access to high quality care potentially will facilitate prevention of secondary complications, reduce the morbidity of complications, promote health, and increase patients' confidence and satisfaction with treatment.

However, there exist a number of critical issues to be resolved prior to the easy and widespread application of telemedicine. Telemedicine has not been adequately tested for delivering care to persons with SCI, nor for persons with other disabilities. In fact, its effectiveness as a diagnostic and therapeutic tool remains largely unknown.¹⁴ Furthermore, the cost of the infrastructure to support telemedicine may be beyond the financial capabilities of many rural communities. Finally, legal and social issues, including licensing requirements for providers of interstate services and liability for rendered services have not been adequately addressed.¹⁴ Overall, telemedicine is a promising but not fully tested healthcare delivery model for rural SCI care.

Area Health Education Centers

The Area Health Education Center (AHEC) program is funded by the U.S. Department of Health and Human Services, but matching funds are often generated to meet the varied missions of the approximately 120 AHEC's. All AHEC's involve partnerships between medical schools and communities and many serve rural areas and facilitate the survival of rural hospitals and boost the number of physicians serving rural communities. For example, the University of Missouri and the Kirksville College of Osteopathic Medicine have teamed up with 23 primarily rural counties in Missouri to provide improved service to these counties and train medical students in these settings simultaneously. One of the core programs of the University of Missouri (MU) AHEC is the Rural Scholars Preadmission Program in which highly qualified rural students, who are committed to practicing medicine in rural areas, are guaranteed admission to the MU School of Medicine. The MU AHEC also uses advanced telecommunications and computer systems, including telemedicine, to link rural providers and students with specialists and other resources at the university.¹⁵


SCI healthcare providers should initiate involvement with rural AHEC's, because these programs provide an exceptional opportunity for improving healthcare delivery for persons with disabilities. Involving physicians-in-training and general practitioners in these programs may significantly improve access to basic rehabilitation needs of persons with SCI.

Rural Institute on Disabilities

The Montana University Affiliated Rural Institute on Disabilities Program is a comprehensive research and dissemination center whose mission emphasizes "full participation in rural life" by "developing and disseminating innovations in teaching, research, community services, and policy advocacy." An example of one of the many rural focused projects of this organization is

identification, prevention, and management of secondary conditions. The most troublesome secondary conditions identified by persons with disabilities in rural areas were problems with mobility, fatigue, joint and muscle pain, chronic pain, and difficulties with access.¹⁶ For persons with SCI specifically, the secondary conditions that were the most troublesome included problems with mobility, access difficulties, chronic pain, joint and muscle pain, physical conditioning problems, and spasticity.¹⁷ Through a case management system in collaboration with CIL's, the Rural Institute on Disabilities is providing outreach workshops that include individualized assessment, educational and informational materials, peer support, and followup services.

Summary and Recommendations

We need to learn more about the barriers to high quality healthcare services for persons with SCI in rural America. There is a dearth of published empirical data on the obstacles to healthcare and community integration or the impact that these barriers have on quality of life. The limited existing information suggests that persons with SCI in rural settings are underserved. Several independent initiatives are beginning to identify the limitations of the current health delivery system and experiment with innovative delivery models, including increasing involvement of CIL's and consumers. Further health services research is needed to identify the critical resources to improve healthcare delivery in rural America. When combined with data from current health delivery experiments, this research will help shape much needed policy for health delivery in rural America. 

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Note

1. To locate telemedical clinics, contact the Telemedicine Research Center at <http://tie.telemed.org>.

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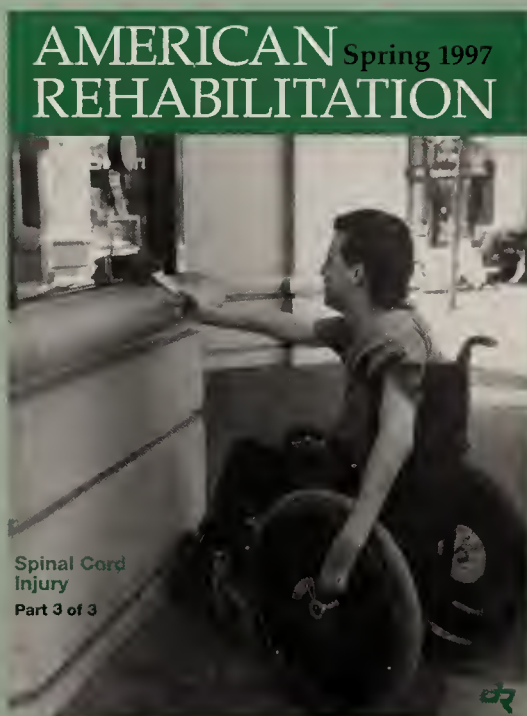
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Spinal Cord Injury and Centers for Independent Living

Max J. Starkloff

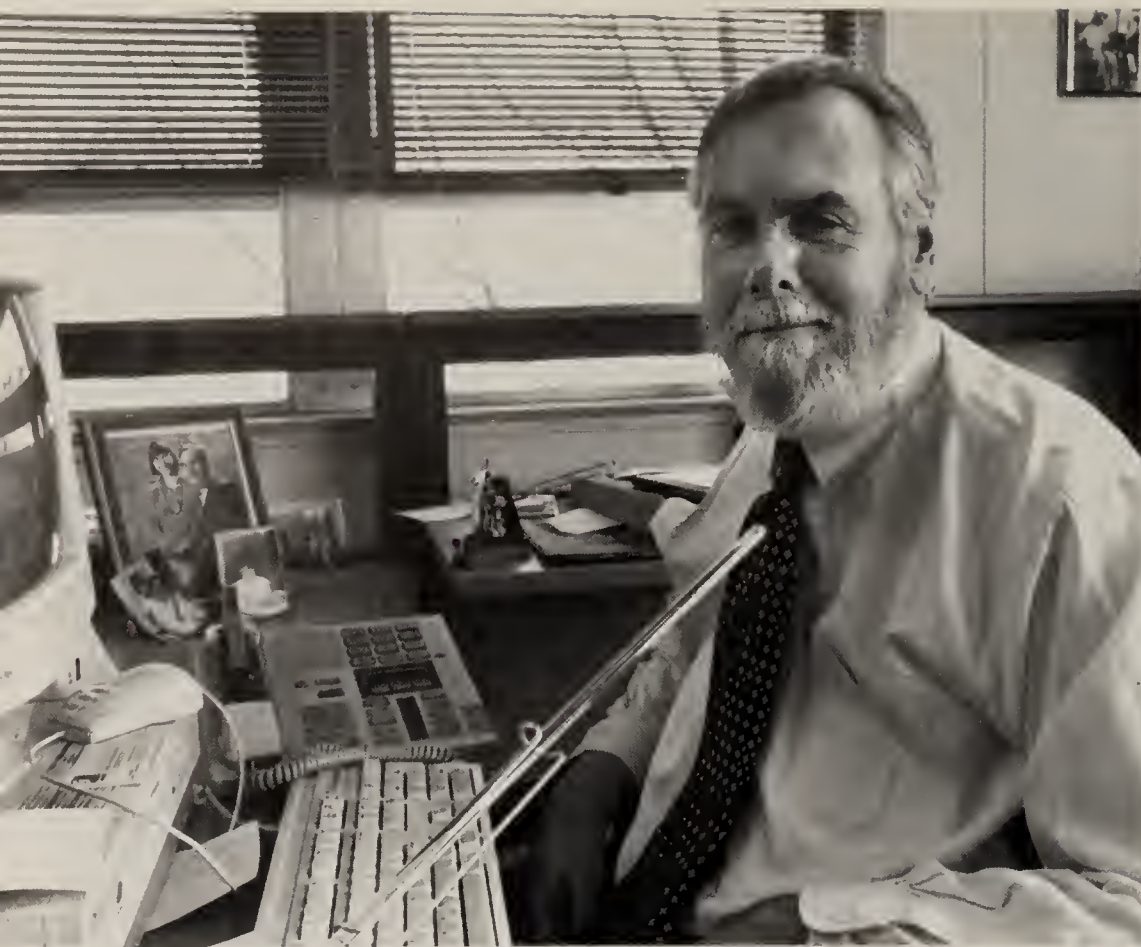
Among the most significant factors that emerge from any study of this country's independent living movement is the key role people with spinal cord injuries have played throughout its history. As the movement began to take shape and gain momentum 30 years ago in Berkeley, California, individuals with spinal cord injuries were among its principal founding members.

I believe a major reason for this level of interest and commitment relates to the unique frustrations people with spinal cord injuries felt over early rehabilitation practices. Often isolated in back rooms or institutions, their few hopes for the future centered around the prospect of being able someday to live independently. A national movement was developing that could give disabled people a voice, and people with spinal cord injuries began to see independence as an opportunity finally to gain real political and economic strength. With its strong foundation of

consumer control and advocacy, this new independent living movement had great potential to become a forceful political movement by attracting a broad, cross-disability population at the grass-roots level.

Many people who had been living with a disability in our society found this innovative philosophy compelling because it provided a spark of hope and optimism. The peer support model within an organizational structure stimulated people to rally behind the movement and begin taking control by creating the means for independence in

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their own communities. The peer support model has given so many of us the motivation to go ahead with our dreams. Others with similar disabilities were living productively, so why shouldn't each of us pursue those same kinds of opportunities? Word about independent living spread throughout those local communities—to rehabilitation centers, nursing homes, and community-based organizations—and the impact was felt immediately.

For far too long, disabled Americans have been overprotected and, consequently, not able to make independent decisions. Independent living was intended to change that, which makes good sense for a variety of reasons:

- Independent living is a consumer-controlled model, giving the individuals affected by its practice authority to manage their own services.
- It focuses on the person's total situation by addressing direct service needs as well as advocacy.
- It works toward educating the entire community about the rights of all people with disabilities.

- It helps transform "tax consumers" into "tax payers." Therefore, it is extremely cost effective.

Today, every legitimate independent living center offers four core services: independent living skills training, peer consultation, information and referral, and advocacy. Of course, most centers offer much more than just the basics. Housing, personal assistance services, outreach, and youth and family programs are excellent examples of other efforts that independent living centers are undertaking in meaningful and innovative ways.

A Personal View

As an individual with a spinal cord injury, I have developed a rather personal appreciation of how the independent living philosophy can turn lives around. I became disabled in 1959 from an automobile accident. My injury occurred at the 3rd, 4th, and 5th cervical level of my spinal cord, which resulted in quadriplegia. I lived at home with my mother for as long as possible,

but financial constraints and the pressure of meeting my physical needs finally necessitated moving into a nursing facility. That was our only choice at the time, and a frightening choice it was. Back in 1959, though, my type of disability was perceived as one requiring a great deal of medical and personal attention; for most people with similar disabilities in those times, there simply was no alternative.

In the nursing home I began filling my time by painting, reading, and studying art history. I took my painting very seriously, but quickly learned how stifling institutions can be for someone who wants to grow and develop. It was maddeningly difficult to get others to understand how serious I really was and, over time, I became quite frustrated. That led to anger and, after 12 years, a life-or-death search for some way to move out on my own.

In those days, the St. Louis, Missouri, community offered virtually no support for people with disabilities beyond the traditional sheltered workshops and recreational type organizations. But I wanted something different, something that would help me move from an institution into the community so I could live independently. It became quickly obvious that this "something different" simply did not exist, so after much discussion with a close friend and many lonely hours of introspection, I decided to take a risk and start my own organization. I was going to be independent, regardless.

It also became readily apparent that what troubled me concerned many other disabled people as well. I was not alone. And not being alone was good. Tireless grassroots advocacy and determined communitywide education would prove to be essential agents for meaningful change. Our reason for being was to achieve full civil rights for people with disabilities; barriers to this goal included an inaccessible community, lack of affordable and accessible housing, high unemployment, and, most daunting of all, the paternalistic and condescending attitudes pervading our society.

Today's Challenges

Alas, many of these problems still exist, and independent living centers still are working hard to change them. The good news is that major advancements have been made, and new barriers are overcome every day. The independent living model continues to gain acceptance as a professional service which plays a significant role in the lives of people with disabilities. Additional efforts are under way to work closely with vocational rehabilitation, medical rehabilitation centers, and other agencies that influence the quality of disabled peoples' lives.

As old barriers are overcome, new ones keep popping up. A good example: as managed care becomes a greater factor in today's healthcare mix, there is grave concern about access to specialized medical services. For example, people with spinal cord injuries have greater potential now than ever before to live healthy lives with minimal secondary complications. At the same time, though, if we don't have access to specialized medical services, we could put our health into critical jeopardy. There are certain healthcare problem areas we need to observe closely to prevent complications. Difficulties such as urinary tract infections, pressure sores, and autonomic dysreflexia,¹ for example, could become life-threatening if not treated properly—and promptly. But with appropriate preventive measures and treatment, people with spinal cord injuries can live long and productive lives.

Independent living centers are playing a pivotal role in the evolution of America's healthcare system by advocating for people with disabilities to have equal access to the best medical care our nation has to offer. Through peer support programs we are offering practical, day-to-day-living consultation to individuals who are newly disabled and looking for advice on what it means to live with a disability in modern society. We offer practical approaches to avoiding secondary complications and carrying on with everyday personal life. Pursuing a career and

having a family are not just possible—they're encouraged.

Too often, people with spinal cord injuries run into significant problems after they are discharged from a rehabilitation center. The reality of having a permanent disability sets in and there is no one available with a similar disability in whom one can confide. Rehabilitation centers need to work directly with community-based independent living centers to assure that when a person is discharged she/he has access to appropriate support services.

Community Outreach

In recent years, independent living centers—primarily through their peer support programs—have taken on even greater importance because of the increase in disability related to violence. In urban areas, the number of people disabled from head and spinal cord injuries by firearms dramatically surpasses those from all other causes of injury. Once people disabled by violence are discharged they often return to an environment characterized by few supportive services, and sometimes by minimal family support. They also lack access to any political power structure that could influence change in their communities. Those individuals, in far too many instances, drop out of sight and reappear only when a major secondary health complication sends them back to the hospital. Urban independent living centers desperately need to develop outreach methodology and funding to address this fast growing crisis.

By building strong outreach programs, independent living centers can establish solid working relationships with neighborhoods and communities. In becoming a vital part of a community's fabric, those centers in turn gain greater access to people who have disabilities; services then can be built around real needs, and, at the same time, centers become well-positioned to educate community leaders about disability rights. And neighborhoods must become more aware of issues facing citizens who are disabled; too often, people with disabilities have to move

away from their communities because they are unable to find accessible housing or because they lack reasonable accessibility to neighborhood amenities. People should be able to live where they choose and not have decisions made for them based on whether they have a disability.

People should be able to live where they choose and not have decisions made for them based on whether they have a disability.

Spinal Cord Injuries and Aging

Another emerging issue today relates to aging with a spinal cord injury. It's certainly an emerging issue for me, since I've been disabled for more than 37 years and am moving steadily closer to birthday number 60. There's a dearth of research available to tell us what happens when a person with a spinal cord injury reaches 60, 70, and beyond, but I believe my energy level at age 59 is higher than ever. Being married and having children ages 17, 11, and 8 may have something to do with that. And besides, a lack of energy just isn't an option for me. My major concern seems directly related to not knowing what to expect when it comes to growing old with a spinal cord injury. Call it fear of the unknown, perhaps. It's only human nature to avoid lengthy examinations of our own mortality, so we don't always focus much attention on what it really takes to go beyond just living a long life; quality of life is important, too. We need to learn more about physical fitness and what can be done to create opportunities for more people with disabilities to participate. For those of us with high levels of quadriplegia, exer-

cise becomes a much more complicated matter. Issues of good access to specialized physicians, exercise, diet, and recreation become at least as important to us as to anyone growing older in America. In the past, disabled people have had relatively little concern about additional complications that come with aging, such as heart disease or cancer, but these too have become topics we must face.

The Role of Technology

Every day, media reports tell us of new and often unfathomable advances in technology. But we absolutely need to learn those new technologies and take every advantage of them. I cannot envision a group more able to benefit from technology than people with disabilities. Computers are enabling us to pursue careers not even possible a handful of years ago and to become more efficient in our daily lives than anyone could have expected. Through computers we now can control our personal finances, do our banking, and play games with our children. And virtual reality has more possibilities for exercise, accessibility, and product design than we can even begin to envision. With developments coming in quantum leaps, it would be foolhardy not to make technology work for us, in every possible way, to improve our ability to live happier and longer lives. Simply put, technology will dramatically affect how one ages and lives with a spinal cord injury, if we seize the opportunity for it to do so.

When we take a look at all of the opportunities available to us in our society, and how they can literally turn around a disabled person's life, centers for independent living have a responsibility to bring organizations and people together from diverse segments of our communities. We need to do a superior job of networking, so those segments can better understand each other. The alliances we build can have a significant impact on educating our society about disability rights and disability in general. It cannot be overemphasized that forming coalitions to ad-

dress specific social or political issues is a major advocacy responsibility of the independent living centers. We need to build and maintain a climate that fosters cooperation and teamwork; stated a bit differently, we have to avoid the infighting that has stalled the progress of other movements.

We need to come together, unified as disabled people, to understand each other's struggles and needs. *Paraquad* has tried to address this by developing support groups. Groups are developed around particular disabilities, gender, and advocacy issues. The spinal cord injury support group has been especially successful, and its members discuss topics ranging from advocacy to community attitudes about people who use wheelchairs. The exchange often leads to people generating ideas about what they need to accomplish in their own lives to live more independently.


Independent living centers exist to help people address their issues, to offer avenues to self-determination for persons with spinal cord injuries as well as those with other disabilities. Whether it be support groups, information and referral, job counseling or peer consultation, independent living services are available over a person's lifetime. And advocacy, whether directed toward one's own life or toward public policy initiatives, affects our entire community.

Independent Living Centers and Public Policy

Independent living centers have gained formidable experience over the past 15–20 years, and today it is imperative for us to put that experience to work. We now know that people—no matter how significant their disabilities—can live independent and productive lives. We have learned that we should not blame the disability for the barriers placed in the paths of people with disabilities. We know the environment can be changed to include all people in the mosaic of American society. Once environmental barriers are removed, people with many differences can be highly productive and valuable

members of our communities. In our society today, we cannot afford to waste a single human being, for every individual is valuable and can lend to making this a better world for all of us.

Independent living centers not only have a responsibility to advocate for societal change, but an obligation as well to understand where people with disabilities are living and why they live the way they do. Once we know where people are living and why, and the kind of support services they are receiving or need, we can then design our services to meet the greatest demand. This information will also enable us to better organize into coalitions and work toward advocating political and social change. Through the development of new support systems and improved utilization of existing support systems, we can assure that disabled Americans are presented the best opportunities in our history to live strong and healthy lives. We must demonstrate to our political and civic leaders and to the general public that the rights of disabled people are not being met. We, as a society, have no choice but to extend to our disabled brothers and sisters the same rights extended all others. No longer can we presume to know what disabled people need or want. We, as disabled citizens, need to speak out and tell our community leaders, our institutions, and our nation what we want. We must be clear. We must be direct. And we must say it often.

Obviously, there is a great deal to do. But the independent living movement has never been in a better position than now to go out and get it done. 

Note

1. *Autonomic dysreflexia* is an abnormal reflex which occurs in people with spinal cord injuries at the level of T6 and above. A noxious stimulus such as bladder distention causes a chain of reflexes which can lead to dangerously elevated blood pressure, sweating, headache, and other symptoms. The condition is treated by removing the offending stimulus and giving the patient medication.

Community Integration of Individuals With Spinal Cord Injuries¹

Wayne A. Gordon, Ph.D.
Margaret Brown, Ph.D.

In considering the ways and the extent to which individuals with spinal cord injury (SCI) have or have not achieved community integration, we would do well to pause to consider what the concept of community integration entails.

First, the definition adopted herein states that "community integration" refers exclusively to non-institutional living, i.e., the focus is solely on people with SCI who are living in nonmedical, noncustodial settings.

Second, community integration refers to a changing and long-term status of the individual. Because the effects of SCI and the individual's adaptations to injury are not static, short term or acute, but rather unfold over the lifetime, the individual's integration into the community must evolve over time. Further, this evolution is a function not only of changes in the structures and functions of the individual's body, but also of a variety of developmental processes; for example, changes in the person's skills at negotiating life as a person with a disability, as well as the abilities and strengths the individual brings to situations—adaptability, intellectual skills, motivation level, and the like. The dynamics of community

integration for an individual with SCI also vary with the ebb and flow of environmental resources, opportunities, and challenges; for example, vocational opportunities that change over time, social support provided within the individual's family and friend network, his or her access to economic resources, the community's willingness to provide opportunities and function inclusively with respect to individuals with disabilities, and the like (Brown, Gordon & Ragnarsson, 1987).

Third, community integration refers to an individual's status within a social-physical environment, i.e., how the individual "sits" within an environment defined by society and by natural law. In this view, four ways of relating to the social-physical environment are central to "community integration":

- characteristics of the individual's residence—type of housing, presence of others in the residence, etc.;
- the individual's vocational and economic role activities;
- his or her integration into social networks; and
- his or her participation in community- and home-based activities.

In sum, community integration encompasses two basics of life: where one lives and what one does within the social-physical context of living.

In fact, as stated above, the "where one lives" component of community integration is a defining characteristic. Integration into the community, at the very least, requires living in a residence that supports and, hopefully, encourages an individual to interact fully with the community. Private homes, apartments, and some group homes are preferable to nursing homes or hospitals for an individual to live life to his/her full capabilities.

From this perspective, the "what one does" component of community integration is crucial in trying to measure the degree to which individuals with SCI living in the community are also integrated into the community. Higher levels of integration into the community require that an individual have a meaningful and culturally appropriate vocational/economic role to play. This may entail working as a student, a volunteer, a homemaker, or as a salaried worker. Community integration also has a social network component. Thus, as the individual is integrated into more complex social groups, including family, friends, community settings, self-help groups, and such, he or she optimizes contacts with others. Finally, the community-integrated individual engages in a variety of activities inside and outside the home that define daily life for active community members (e.g., travel to work/school, grocery shopping, going to movies, dining out, cleaning house). In sum, in this approach we must look at vocational/economic roles, social network involvement, and patterns of daily life activities to determine where individuals with SCI fit on the integration continuum—from "only just there" to "fully active" in and interwoven into the fabric of the community.

Although one can measure (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993; Whiteneck, Charlifue, Ger-

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hart, Overholser, & Richardson, 1994) the degree of integration of an individual with SCI into the community and the ways in which people with SCI participate in community living (or do not), this does not imply that one can say what is successful versus unsuccessful community integration. Success, we believe, is defined individually and is determined by a person's achieving a life consistent with his/her hopes and aspirations; success must be insider-driven rather than outsider-dictated.

In this article, recent literature on several aspects of community integration of individuals with SCI will be discussed, adhering to the four-part concept of community integration defined above: where one lives, vocational/economic roles, engagement in social networks, and involvement in activities in the home and community.

Where One Lives. Recently published data from the National SCI Model Systems database (Dijkers, Abela, Gans, & Gordon, 1995) indicate that, following initial rehabilitation, most individuals with SCI (92 percent) are discharged to private residences in the community. Nursing home discharge was associated with three variables:

- Age: Close to 30 percent of those 70 or older, compared to about 2 percent of those younger than 20, were discharged into nursing homes.
- Marital status: Higher rates of being discharged into nursing homes were seen amongst divorced (9 percent), separated (11 percent) and widowed persons (24 percent), compared to those who were single or married (4 percent).
- Severity of injury: Tetraplegics were more than twice as likely to be discharged to a nursing home than paraplegics (8 percent vs. 3 percent). Dijkers and colleagues (1995) suggest that these findings point to self-care and health needs that far exceed what available support systems—largely family members—can provide.

Vocational/Economic Roles. A vast literature exists on return to work following SCI (see Trieschmann, 1988, for an extensive review of this literature). While much of this work has focussed on isolating psychological traits asso-

ciated with working, many of these studies are methodologically weak. On the whole, they suggest that return to work is related to three variables:

- Degree of impairment: Paraplegics are more likely to return to work than tetraplegics, and, within each group, those with incomplete injuries are more likely to work than those with complete injuries.
- Age: Those who are injured younger are more likely to return to work.
- Rehabilitation experiences: Completion of a vocational rehabilitation program increases the likelihood of returning to work (DeVivo, Rutt, Stover, & Fine, 1987).

In looking at vocational and other economic roles, researchers have found that access to resources can affect economic role functioning. For example, in a study of the impact of electronic control devices on the activity patterns of individuals with SCI, Efthimiou, Gordon, Sell, and Stratford (1981) found that the use of electronic control units was associated with increased frequency of participation in educational activities, increased independence, and decreased inactivity. In another study of individuals with SCI, Brown (1983) found that access to a private vehicle increased the probability of being employed from 0 percent to 50 percent.

Thus, return to work appears to be related not only to demographic and impairment variables—relatively immutable characteristics—but also to environmental factors—which can be changed through accessing resources and through the provision of services (e.g., personal care assistance, electronic control units, accessible transportation).

Examination of the SCI National Model Systems database (Dijkers et al., 1995) reveals that, by the first year post-injury, 16 percent of those who at the time of injury were working have returned to work, and 8 percent have entered school; more than 70 percent consider themselves to be unemployed. Employment following SCI increases steadily, until at 10 to 11 years postinjury one-third of those in the database were working. Thus, re-entry (or initial

entry) into the world of work after SCI is a slow process, which, for any cohort of individuals, may span a decade or more; but two-thirds of this population appears not to move out of unemployment at all.

In terms of continuing or resuming an educational program following SCI, data from the National SCI Model Systems database (Dijkers et al., 1995) indicate that about 15 percent of this group had improved their level of education after injury. Of interest was the finding that, at 5 years after injury, those with SCI had somewhat less education than the general U.S. population, but by 10 years postinjury those with SCI were somewhat better educated. Thus, SCI appears to trigger changes that lead to engagement in education at a level beyond the norm for the United States.

Despite the results summarized above, it is difficult to explain why only about a third of those who sustain an SCI enter the work force within 10 years of injury, when about twice this number were working at the time of injury. Further, many individuals with SCI are injured during their years of educational preparation for entry into the work force. If SCI had not intruded, one would expect that most of these students would within a few years enter the work force as they complete their educational programs. Thus, the small percent of people with SCI working 10 years after injury reflects both those who had been working and did not return to work or remain in work as well as those who never attempted age-appropriate entry into the work force. This high level of unemployment results in a personal loss to the individual, as economic and other satisfactions of work are foregone and a large part of the day is left unoccupied, as well as an economic loss to society in terms of benefits paid out, lost tax dollars and reduced economic growth.

While clearly SCI can be a barrier to some forms of employment—jobs requiring manual labor or extensive mobility, for example—it does not preclude most other forms of work. And, even though many individuals with SCI participate in educational programs, this

appears to lead at most to marginally increased employment. It is clear that many elements, personal and societal, some of which remain unidentified, discourage the return to work. At the personal level, clinical evidence suggests that many people who experience SCI are left bereft of a compelling vision of their future. They are lost in what no longer exists for them and do not find their way through to envision a positive future for themselves.

At the societal level, factors such as social security disincentives and environmental barriers bar access to the workplace for many. Disincentives weigh heavily against return to work, as many individuals with SCI cannot, as wage earners, afford the necessities of life with SCI that are provided to unemployed individuals with disabilities through publicly funded programs. These deterrents are amenable to intervention, if society chooses to invest in the inclusion of people with disabilities, including reasonable accommodations to their needs.

Activities and Social Networks. Brown (1983) and Brown, Gordon, and Ragnarsson (1987) compared the activity choices of well-matched samples of people with SCI (N=22) and those without a disability (N=22). She raised the question of the degree to which the effects of SCI would be encountered in daily life if resources of individuals with SCI were optimized. The two samples were matched on such variables as gender (all male), age (mean = 39, range = 20-53), residence (most participants lived in the suburbs with an average of two other people living in their residence; 13 lived with children), vocational status (all participants were working, except for one person in the nondisabled group who was a student), income (mean SCI = \$47,000; mean nondisabled = \$52,000), access to automobiles (all participants owned and drove their own cars), and education (15 of those with SCI had advanced degrees vs. 12 in the nondisabled sample).

In terms of use of their time, the groups were similar in most categories of activity (vocational, inactivity, personal care, TV, quiet recreation, social-

izing, and travel). However, those in the nondisabled group did spend more time participating in household tasks and in active recreation categories. Thus, for most types of activities, time use was *not* a highly sensitive indicator of impairment, given optimal resources.

The picture was different when another aspect of activity choice was examined: the frequency of activities engaged in, which is an indicator of activity tempo (or the proclivity/ability of an individual to switch freely from one activity to another). When activity choice was examined in this manner, those with SCI participated in 20 percent fewer activities than did those without a disability. This reduction in activity tempo was not uniform, but instead was restricted to the categories of personal care, household tasks, active recreation, and travel activities. It appears that individuals with SCI adapt to their impairment by doing some things less often, which seem to be activities in which a large expenditure of energy is required, architectural barriers are likely to be encountered, and/or assistance is likely to be needed.

Based on the activity duration and frequency measures, it was reasoned that the impact of impairment would be highlighted in terms of the time spent in each occurrence of an activity: Those with SCI would do certain things longer, in each instance of certain activities. Specifically, it was found that those with SCI spent 25 percent more time in each occurrence of vocational, personal care, and socializing activities. Apparently, in order to reduce the cost in energy of shifting activities (for example, interrupting one's work activity to socialize every now and then with coworkers) and to maximize low-energy, pleasurable activities (for example, socializing) or because certain types of tasks may simply take people with SCI longer to complete than people without a disability (for example, dressing), people with SCI do tend to spend more time in certain activities whenever the activity occurs.

Even though the two groups of individuals were well-matched and had considerable resources available to

them, those with SCI still evidenced patterns of activity somewhat different than those of persons without a disability. Their disability limited the extent of their participation in activities both at home and in the community. Nevertheless, the differences were quite small—clearly smaller than would have been the case if the comparison had been between two low-resource groups of individuals, one with SCI and one nondisabled. High-level resources, these data suggest, help minimize differences and optimize opportunities for community integration.

Was the SCI sample less successful than the nondisabled group in terms of community integration? Some of Brown's data (1983) suggest that success was unrelated to group activity differences. Specifically, the two groups did *not* differ in their ratings of satisfaction with their daily life activities and how they spend their time. It appears that these high-resource individuals with SCI had learned to adapt to their lives as lived; their activity choices and degree of integration into the community differed somewhat from the nondisabled group, but their satisfaction with daily life did not.

Discussions with many people with SCI and those with other types of severe disabilities, e.g., traumatic brain injury, stroke, confirm that, after onset of a disability, doing things—both at home and in the community—becomes more time consuming, often to the point of exhaustion. This point was recently made by the literary agent Robert McCrum (1996) when discussing the impact of his stroke:

"Six months ago, I could slip across the street to post a letter in the time that it takes to type this sentence. Now I would have to raise myself up from my chair, find my cane, limp to the front door (say, 3 minutes), negotiate the steps to the street, and make my way to the corner (roughly 5 minutes), and then hobble back and collapse, exhausted on the sofa, as though I had just run a marathon. Every day, I am acutely reminded that there is a world out there, a world I cannot be part of in quite the same way. . . . I have become

friends with slowness, both as a concept and as a way of life" (p. 118).

This is from an individual with a recent stroke. But, Brown's data suggest that for some with SCI, with much longer-term impairment, there is also an accommodation with their injury and its impact—its "slowness, both as a concept and as a way of life."

Discussion


Individuals with SCI live their lives in the community learning, more or less well, to adapt to and negotiate the sometimes conflicting paths of who they are and who they want to be. Indeed, this process is part of life for each of us, as we try to minimize the discrepancy between current reality and valued goals. When people have had a spinal cord injury, this reconciliation process is made more difficult because they must confront the additional discrepancy between who they were before injury and who they are now. In other words, the person with SCI must come to understand how his or her disability moderates or alters dreams and hopes, while still maintaining hope and staving off despair.

The data reviewed indicate that most individuals with SCI have largely achieved the minimal level of community integration, i.e., over 90 percent reside in the community after rehabilitation discharge. But in other ways, their integration appears tenuous at best. It may be that only about one-third of those with SCI return to work because they have not been encouraged or helped to develop a new set of hopes. We often forget that a spinal cord injury does not destroy a person's need to dream and hope, or whatever we wish to call a desire for something better for oneself. All people benefit when supported in their quest toward their dreams, but this is a *sine qua non* for individuals facing a dramatic shift in life's circumstances, such as SCI.

As discussed above, social-physical environments hinder the individual with SCI in a variety of ways. Part of this hindrance may reside in the way in which the media portrays people with spinal

cord injury—narrowing the public's views and attitudes toward them. People with SCI are portrayed, on the one hand, as helpless victims of unfortunate events—people whose bodies become their prisons, or, on the other hand, as "supercrises"—people who are spoken of as "heroic" and "inspirational" (Koplow, 1996). The stories of Dennis Byrd, Travis Roy, and Christopher Reeve, indeed, are heroic. But, no matter the form of the presentation, it is clear that when people with SCI are defined as heroes or victims, they are also defined as being directly (and often solely) responsible for their fate. The corollary is that the social-physical environment is "off the hook." Thus, the "victim" is the person who is (sadly) unable to adapt to the world of the able bodied, and the "supercrise" is the person who (heroically) meets the challenge. The world is absolved of its responsibility, as it is the injured person who either "does it or doesn't" (Koplow, 1996).

The emphasis of this article has been on the individual-within-the-environment, rather than the individual-as-island. Indeed, community provides the context for the failure of "victims" of SCI and for the success of "supercrises." We have seen how access to personal, societal, economic, and social resources within the personal community and in the wider society can level the barriers to integration into community life. It is also clear how the dynamics of adaptation and integration are slow-paced for most. More data are needed to define the resources most essential to successful integration, however "success" may be defined.

In the meantime, no research at all is needed to identify a resource universally needed: encouragement by family, friends, and the wider community to pursue our dreams and goals. Spinal cord injury does not change this need for broad-based support. 

Note

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Preventing Spinal Cord Injuries Through Safety Education Programs

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"It was just a leisurely day...", "Didn't have a care in the world...", "I was a passenger...", "I didn't know what 55 meant...", "Dove into the water...", "That was it, first and last time..."—Words spoken by survivors of spinal cord injury as they try to describe the incident that changed their lives forever. These young adults are trying to make an impression through their candid conversations in the film, "Harm's Way," sponsored by the American Academy of Neurological Surgeons and Congress of Neurosurgeons. Their message? "Think First!" "Don't take foolish risks!" "Prevent the injury from happening!"

Injuries in general are beginning to get the recognition they deserve as serious health problems. *Healthy People 2000*¹, published in 1990, sets goals and priorities for health promotion, health protection, and preventive services. This comprehensive report states, "Spinal cord injuries are catastrophic health events resulting in enormous human and economic costs." The State of California, in recognizing the work done in the report, *Recommendations for Research on Spinal Cord Injury in California*, has continued the effort at reducing spinal cord injuries (SCI) by making specific recommendations.^{2,3}

Healthy People estimates of SCI in the United States range from 2.8 to 5 per 100,000 people. In California, there may be as many as 35,000 people with SCI, with about 1,000 new injuries occurring each year.² Estimated lifetime costs for medical treatment and rehabilitation of SCI can be as much as \$750,000 per individual. The economic costs are

staggering. Depending on the method used to measure costs, estimates are approaching \$200 billion per year.³

Background

The spinal cord is an extension of the brain, and sends electrical impulses to and from the brain. The brain controls movement, sensation and bodily functions. A spinal cord injury (SCI) is paralysis, to a greater or lesser extent, as a result of damage to the spinal cord. The cord is protected by 33 vertebrae. The vertebrae are generally grouped into four sections: cervical, thoracic,

lumbar, and sacral (illustration). Depending on the level of injury, the paralysis is described as tetraplegia (or quadriplegia), referring to all four extremities affected, and paraplegia, referring to paralysis from approximately the waist down. There is no known cure for an SCI, and the results of the injury are considered permanent.

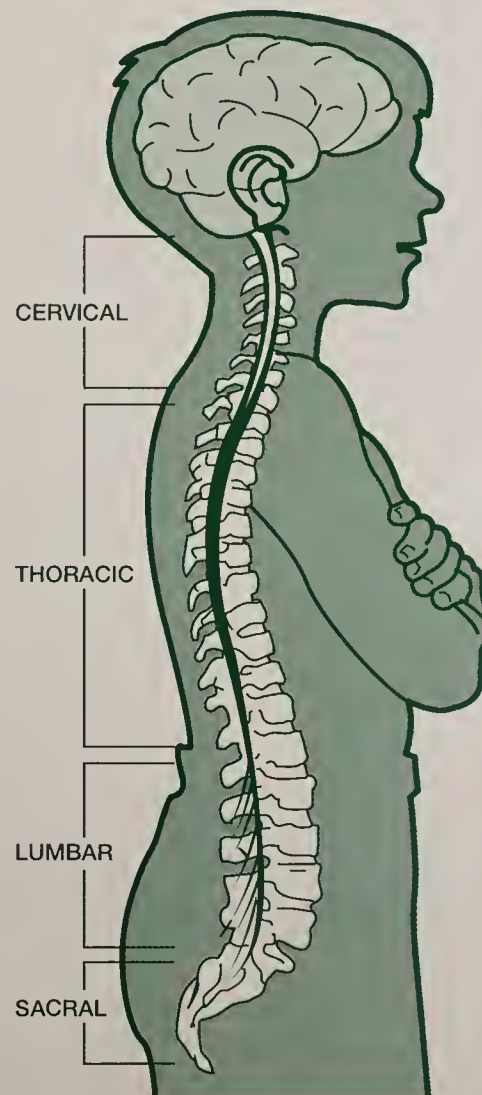
SCI can occur in a number of ways, but we will focus on traumatic injuries, that is, those injuries caused by an external force. The population most at risk for SCI are young males, 15 to 25 years of age. The most frequent cause of injury is motor vehicle crashes (including motorcycle), followed by falls and sports. A most alarming trend, however, is the increased incidence of injury because of violence/violent behavior.

The multiple consequences of SCI—including permanence of injury, risk to our youth, and economic impact—demand that we use every means at our disposal to prevent the injury from occurring.

Types of Prevention

There are several ways to categorize prevention efforts: *primary*, *secondary*, and *tertiary* prevention.

Primary prevention seeks to "reduce susceptibility, eliminating or minimizing behaviors and environmental factors that increase the risk of injury."³ Environmental, legislative, and educational activities are examples of primary prevention.



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Definitions

A disability is a functional limitation that interferes with a person's ability, i.e., walking, hearing, learning; handicap is defined as "a disadvantage for a given individual that limits or prevents the fulfillment of a role that is normal (depending on age, sex, social, and cultural factors) for that individual. Handicap encompasses the individual's role in the family and community.⁴

Secondary prevention is the effort aimed at reducing or halting the progression of the disabling condition after the initial injury has occurred (i.e., specialized emergency medical services for those who sustain an SCI).

Tertiary prevention refers to preventing or limiting conditions associated with the SCI such as decubitus ulcers (pressure sores), and contractions. Secondary and tertiary levels of prevention work in concert to prevent the disabling condition from becoming a handicap.

Primary Prevention

A number of agencies, institutions, and organizations have worked to form strategic plans to address injury prevention. The three broad approaches for injury prevention programs are:

- *Environmental Modification.* Engineering has addressed the need for passive intervention in prevention—the installation of air bags in passenger vehicles, shock absorbent guardrails on the highways, improved lighting—all of which contribute to making our environment safer.

- *Legislation* that requires change in behaviors. Several laws have been passed in California which require helmet use on motorcycles, more stringent guidelines on child occupant seats, mandatory helmet use for bicyclists under the age of 18, and lowering of

blood alcohol content required to qualify as driving under the influence (DUI).

- *Education* of persons at risk for injury. These programs are designed to give information about the types of injury, how these injuries occur, what people can do to minimize risks, and why it is worth their effort to do so.

The rehabilitation professional is most often able to influence the reduction of injuries through education. In order to make a significant change in an individual's behaviors, he/she must first be aware of the problem. Santa Clara Valley Medical Center (SCVMC), together with the Traumatic Brain Injury (TBI) and SCI Model Systems (programs funded by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education) support an educational program to middle and high school students. The Safety Education Program at SCVMC has reached more than 82,500 people, including those in several special programs supported specifically by law enforcement agencies in Santa Clara County.

All of the following programs described can be easily replicated in any community and can be modified to address the community's needs. Most importantly, they provide a unique forum for members of the community to become aware of the consequences of high risk behaviors.

Disability Awareness and Injury Prevention Presentation

The school presentation, commonly known as THINK FIRST,⁵ is a national program with over 200 chapters in 47 states sponsored by the American Association of Neurological Surgeons (AANS) and Congress of Neurological Surgeons (CNS). Directed at middle and high school students, this presentation seeks to reduce the incidence of injury.

The presentation, which can be given in either classroom or assembly format, includes a rehabilitation professional describing brain and spinal cord injury, an action-filled video⁴ featuring direct testimony from teenagers, and a person who has survived a brain or

spinal cord injury discussing his or her injury in terms of financial, physical, and emotional consequences. Finally, strategies for preventing these injuries are discussed. The audience has an opportunity to ask questions throughout the presentation and, time permitting, students are asked for feedback. Typical responses indicate the students understand that injuries could happen to them and that they intend to modify their behavior (i.e., wear safety belts, measure the depth of the water, refrain from drinking while driving).

The rehabilitation professional uses anatomical models to illustrate the various types of injury and their consequences, which are described in terms of loss of physical, cognitive, or social function. The featured video—either "On the Edge" or "Harm's Way,"—is designed to catch the audience's attention and does so through young actors describing typical activities to which the audience can relate. A speaker, who has a spinal cord injury, then narrates his/her personal story. This is a very poignant part of the presentation, as the survivor, speaking from the heart, shares a most personal account of the changes in his/her lifestyle. For many in the audience, this is their first opportunity to meet with someone who has a disability and to question him/her openly.

The Juvenile Traffic Safety Diversion class is presented by the City of Sunnyvale, California, Public Safety Division. Sunnyvale, a city in the heart of Silicon Valley with a population of approximately 126,000, is unique in that the police and fire departments are combined. The city offers first-time offenders under the age of 18 an opportunity to attend an education class in lieu of paying a fine for a bicycle, skateboard, or pedestrian violation. A parent is required to attend also. The primary goal of this program—which is similar to THINK FIRST but modified to emphasize bicycle and pedestrian safety—is to teach juvenile traffic offenders their rights and responsibilities. It is given one or two times per month in a classroom format.

The Juvenile Probation and the Adult Daily Reporting Programs. Juveniles who have been convicted of substance abuse violations are required to attend our presentation as a condition of probation. They are joined with the inmates from the Adult Daily Reporting Program. Adult Daily Reporting is a 6-week alternative sentencing program which addresses lifestyle, decision-making, self-esteem, and work skill issues with selected inmates of the county jail. The presentation is modified to address issues such as substance abuse, violence, and violent behaviors, with the intended goal of reducing the incidence of SCI among young adults. A tour of the rehabilitation facility is included.

Safe Alternatives & Violence Education. (S.A.V.E.) This presentation is offered by the City of San Jose to students who have possessed weapons on or near a school campus. The educational cur-

riculum is designed to offer information and alternatives to students and the material is presented in a large group format (parents are required to attend) followed by small group focus sessions to process the information. This is a particularly exciting program in that it is designed for the less sophisticated offender and has specific reinforcement activities. Those who remain violation free for 6 months are invited back for a "reunion." Food, guest speakers, and positive reinforcement activities are offered. Santa Clara Valley Medical Center and the Model Systems provide guest speakers at the reunion and audiovisual materials for the S.A.V.E. Program.

Evaluation

Do these types of programs really work? It is extremely difficult at this stage to present accurate data that con-

clusively show how successful these programs are. However, several studies^{6,7} indicate children have learned they are at high risk—"It *can* happen to me." Student/parent/instructor feedback forms indicate an intent to change behaviors that increase the risk of injury: "I'll wear my seat belt 100 percent of the time," and "I thought wearing a bike helmet was stupid . . . now I see that it could save my life."

Evaluation of some of the presentations included a pre and post survey to selected classes and an instructor evaluation form, reported elsewhere.⁶ Recently reported was a testimonial from a family in New York whose children found guns on a trail near their home.⁸ They had just received a presentation about gun safety, and instead of picking the guns up, they ran for an adult. The sheriff who responded to the call found a rifle and pellet gun, both loaded.

Another indication that the program is successful is the number of requests for "repeat performances." Each year, instructors are sent a letter describing our program, along with a "Request for Presentation" form.

Additionally, officers from the Sunnyvale Juvenile Traffic Diversion Program and the officers in San Jose and Santa Clara County all report a reduction in violations that they attribute to the program.

Benefits

The THINK FIRST prevention program format was originally designed to increase knowledge and alter behaviors. It is, however, difficult to assess the impact of any one prevention effort on the acquisition of knowledge and the incidence of targeted behaviors, let alone the impact on actual event nonoccurrence (i.e., the prevention of even one injury). An evaluation of our program⁶ was able to demonstrate an increase in the knowledge of high school students (i.e., recognition that TBI and SCI happen most frequently to individuals of high school age and that these injuries usually result from motor vehicle accidents).



Richard Patterson speaks to a group of students at Independence High School in San Jose, CA. (Photo, courtesy of Marcio Sanchez, *Spartan News*, San Jose State University.

On an experiential basis, there appear to be many additional benefits to the Safety Education Programs. The audience is given information not otherwise available in a very supportive environment. The idea that they need to think of the possible consequences of their actions is presented to them in a nonlecture format. They are introduced to and given the chance to question, without embarrassment, an individual with a disability. With this intimate contact, the audience can learn respect for people with disabilities.

Survivors are uniquely able to speak to an audience at a personal level. One speaker says, "These presentations not only help me make sense of what I'm going through, they also help me deal with the losses I've experienced." In speaking to a variety of people, survivors can be positive role models for disabled and nondisabled individuals. Survivors can use the experience of presentations to demonstrate their reliability and work skills. On a personal level, the presentations are a real confidence booster.

The community benefits as a whole. If just one spinal cord injury is avoided, the savings estimate is between \$110,000 and \$240,000 alone.

Because of the very nature of adolescence, preventative education programs are extremely valuable.

Considerations

Because of the very nature of adolescence, preventative education programs are extremely valuable. Teenagers can perceive themselves as immortal, invincible, and infallible. Barbara Staggers, M.D., M.P.H.,⁸ describes some of the characteristics of adolescence as follows: The focus of early adolescence (ages 10–14) includes

concentrating on relationships with peers, preoccupation with development, and exploration of the new-found ability to abstract. During middle adolescence (ages 13–17), youth are having major conflicts over independence, and their peer group sets behavior standards. Late (ages 16–?) adolescent characteristics may include the ability to accept/reject advice, have a defined role with respect to society as a whole, and solidify body image and gender role. Given this brief description of the turmoil that is part of normal adolescence, it is easy to see why it is so difficult for individuals most at risk to believe that they are indeed at risk.


Scheduling and cost are concerns in any prevention program. We want to reach the largest number of students possible, but schools may not be able to accommodate an assembly, so classroom presentations are the alternatives. Teachers are struggling to fit all the required classes into a limited timeframe, so creative integration of the presentation into existing classes is imperative. Resources, i.e., speakers and staff, are limited. Many programs rely on volunteer staff to help reduce some costs, but more education to funders on the importance of prevention efforts is needed. Keeping in mind that the estimated lifetime costs for medical treatment and rehabilitation of spinal cord injury can be as much as \$750,000 per individual, the cost vs. benefits of a prevention program are well worth the investment.

Future Directions

Environmental and legislation campaigns have made a great contribution to reducing the number of spinal cord injuries. We must continue to support these efforts by informing and educating the public about the personal and societal costs of injury. Communities as a whole must agree to support safety education programs. Collaborative efforts between legislators, public healthcare officials, education providers, and consumers will effectively utilize limited resources.

Safety education programs should be ethnically sensitive. Many cultures have specific expectations or taboos in

childrearing, and successful programs will address those issues.

While the presentation appears to have a positive impact on the students, "one-shot" programs are clearly insufficient to alter risk-taking behavior that may lead to injury. Injury prevention programs should span the life cycle, with emphasis on early programs. THINK FIRST for Kids⁵ is one effort to integrate the safety messages with the established curriculum for grades 1–3. 

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Aging with Spinal Cord Injury

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Aging: a Complex Topic

Many myths surround aging. One of the most common is the belief that getting older means being ill. Another says that older people are less physically and mentally active. A third common myth is that older people have a poorer quality of life.

These tales arise partly out of our fear of the unknown and partly out of our belief that aging is a wholly negative process. And, aging is not without its negative context. Undeniably, aging is evidence that life is transient and relatively short, proof that we have limited internal resources and defenses against countless external forces—one of which is time itself. Indeed, aging is not a preventable process; it is something that all humans will encounter. It may occur at different rates and at different ages and in different ways for each person, but it will occur.

Unfortunately, differentiating normal aging from a host of other medical, so-

cial, environmental, chemical, physical, and psychological processes is virtually impossible. For example, are heart problems, cancer, or even just changes in the appearance of our skin or in our visual acuity a result of growing older or are they the result of specific environmental or chemical exposures or genetic makeups that have nothing to do with age? Indeed, all are highly interactive, all effect the aging process. How then do we separate aging from these other issues and influences?

If aging is a complex topic, superimposing a disability—like spinal cord injury (SCI)—only complicates it further. In addition to all of the above “normal” aging-related processes, disability brings its own questions, theories, and conceptualizations. In the World Health Organization’s conceptualization of disablement,¹ there is impairment—an abnormality of structure or function, for example, spinal cord damage at the C5 level. There is also disability—the dependencies and limitations that result from an impairment, such as not being able to walk, to dress, to live independently. There is handicap—the social barriers that result from impairments and disabilities, like not being able to work, to raise children, to be involved in the community. And, of course, there are complications and secondary disabilities and other issues that come later, after the initial disability. Some are medical, some are physical, and some are psychosocial. All impact and interact with the aging process and illustrate how both the topics of aging and disability are clouded and confused by a plethora of terms, concepts, and issues. In the end, it becomes very difficult to separate normal aging from medical complications and from the initial disability and its own complications.

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When are a spinal cord injury survivor's chronic infections, depression, or painful shoulders just part of normal aging? After all, nondisabled people may have these very same problems. When are they a sign or a result of accelerated aging caused by the spinal cord injury? When are they neither and, as some might argue, when are they just coincidental secondary impairments and disabilities—medical problems that are unrelated to either SCI or to aging? What happens when such problems occur within the context of a long-term SCI survivor's changing living situation—a divorce, an aging caregiver, a lost job, a changing neighborhood that the survivor no longer feels safe in? As a result of this confusion, are true medical complications or psychosocial concerns—treatable problems—being passed off as expected age-related issues? Or, on the other hand, are we vainly struggling to “cure” problems that really are nothing more than normal aging? Are these questions just academic? And, do we care about their answers? To this last we must respond “Yes!” if how we answer affects how we understand long-term spinal cord injury and how we interact with and treat the long-term spinal cord injured individual.

Longitudinal Research

Indeed, the issue of aging with a spinal cord injury is a complicated one. We need to approach it scientifically to learn “what’s what.” Here the concept of longitudinal research becomes important. Studying the same group of people over time helps us to understand the interrelationships of all of the issues described above and, most important, to understand risk factors.

In fact, there has been a fair amount of longitudinal aging research done. Thousands of people have been studied over long periods of time to track changes with age. Three well-known aging studies include the Baltimore,² Duke University,³ and Framingham⁴ studies. However, important as these studies have been in expanding our knowledge of physiological aging, the relationship

between disease and aging, or of risk factors for later impairments or morbidities, they have not addressed the aging process as it affects people with disabilities, particularly those who have spinal cord injuries. None examines how the normal aging that occurs in a body system impacts the person aging with a superimposed spinal cord injury.

Until very recently, there has been little research particularly designed to study aging in people with spinal cord injuries.

Until very recently, there has been little research particularly designed to study aging in people with spinal cord injuries. One of the difficulties in studying aging in this group is the wide degree of variation that exists; depending on the neurologic level itself or how severe the disability is, or on the age and a range of other characteristics of the survivor and his or her environment, outcomes may be very different.

Thus, research has been needed which could focus on uncovering common variations or risk factors over time. One of the first attempts to conduct such longitudinal research has taken place in Great Britain under the leadership of the Rehabilitation Research and Training Center on Aging with Spinal Cord Injury, Craig Hospital, Englewood, Colorado. That team, funded by both the Centers for Disease Control and Prevention and the U.S. Department of Education's National Institute on Disability and Rehabilitation Research, has been working with two of the world's oldest SCI treatment facilities, both located in England—the National Spinal Injuries Centre at Stoke Mandeville Hospital, in Aylesbury, and the Regional Spinal Injuries Centre, in Southport—to track more than 800 individuals with long-term spinal cord injuries.

To date, three phases of the British study have been completed, one in 1990, one in 1993, and one in 1996. Analysis of the third phase is currently underway. People selected for the study had injuries which were traumatic and occurred over 25 years ago. They had to be between 15 and 55 years old at the time of the injury, thus eliminating children, whose needs are very different from those of adults, and older persons who were already well into the aging process before their injuries occurred. To be eligible for the study, participants had to have lived, at the time of injury, in one of 13 specific counties served by the two hospitals. This was to ensure the most population-based sample possible. Finally, participants also had to have been admitted to one of the two spinal centers within 1 year of injury and had to have survived for at least 1 year following the injury. This was to exclude individuals whose early hospital records may have been less complete or who might not have received state-of-the-art early care and to ensure that the research focused on complications, problems, and even deaths that were related to the aging process rather than to the initial injury itself.

Eight hundred and thirty-four people were identified who met all the selection criteria. As is still typical of spinal cord injury demographics today,⁵ there were substantially more men than women—87 percent were men. Almost half of the participants—42 percent—had been injured in their late teens and early twenties. The majority, however, were injured between ages 25 and 34. Approximately two-thirds of the participants had paraplegia, while a third had tetraplegia—a distribution that probably reflects differences in the survival outcomes of several decades ago.

The spinal center medical records were reviewed for all eligible participants to identify a range of variables, most importantly, a history—via documented ICD9 codes⁶—of their health and medical issues and complications. British vital statistics and death records also were reviewed to identify those who had died up to the time of the 1990 investigation.

Four hundred and twelve of the original eight hundred and eighty-four people were known to be alive. Three hundred and fifty-two were successfully contacted in 1990 and 282—80 percent—agreed to participate in an additional, ongoing study. They underwent a physical examination, range of motion, sensory and muscle testing, an electrocardiogram and chest x-ray, complete blood and urinalysis, and vital capacity assessment. They also completed lengthy surveys about their perceived health and health problems, and completed several psychometric instruments designed to quantify well-being, life satisfaction and quality of life. Three years later, 227 of these returned and repeated the examination and evaluation process. This time, measures of depression and perceived stress were added and their spouses were interviewed as well. What follows is an overview of the findings of this comprehensive longitudinal study.



Death Rates and Causes of Death

Death data were obtained by reviewing medical records and by contacting Great Britain's Office of Population Censuses and Surveys. These reviews established that the British SCI survivors did have a higher death rate than the general population. Twenty-year-olds had a death rate (7.2 per 1,000) that was eight times higher than their 20-year-old nondisabled counterparts (0.9 per 1,000). By age 70, the death rate in the SCI population had increased to 75.1 per 1,000. However, this was now only one and one-half times higher than 70-year-olds in the general population (50.2 per 1,000), indicating a decreasing mortality ratio despite an increasing mortality rate.⁷ This decreasing death ratio was noticed both as survivors got older and the longer they were hurt.

Among those of the 834 who had died prior to 1990, problems with the kidneys and genitourinary system were the most frequent causes of death, accounting for just over 24 percent of all the deaths, a proportion substantially greater than in the general population. Cardiovascular-related prob-

lems were the second leading cause of mortality, accounting for 23 percent of all of the deaths. Included were heart attacks, strokes, and other heart and circulatory complications. Compared to the general population, death rates for cardiovascular disease tended to be only slightly higher;⁷ however, the deaths did appear to be occurring at earlier ages.

Respiratory causes accounted for 14 percent of all deaths and in all age groups the death rate from respiratory illnesses was higher than in the general population.⁷ The remaining causes of death—injuries, cancer, septicemia, and others—were relatively infrequent.

Between 1990 and 1993 another 15 persons had died. Their causes of death were similar to those of persons who had died prior to 1990—cardiovascular disease, pneumonia, septicemia, cancer, and suicide. This listing is very similar to what is reported by the U.S. National SCI database,⁵ for individuals dying 5 or more years after their initial injuries.

The records of these 15 individuals were examined to identify significant differences between them while they were still living and the study partici-

pants who had not died. Those who died did not differ with respect to gender, length of injury, or severity of their disability; however, they did consume more alcohol, and those who were smokers had smoked longer—but not more per day—than survivors who were current smokers. Those who died had smaller lung capacities when they were examined in 1990 and had more evidence of severe hydronephrosis. When surveyed in 1990, those who later died also were less independent, got out and about the community less often, and described themselves as generally less healthy than other study participants. Interestingly, however, they were less likely to have described the years just before their death as the dreariest part of their lives.

Morbidity: Illnesses and Complications

Data examining morbidity—illnesses, complications, and medical problems—were collected from the personal interviews, during physical examinations conducted by an SCI-trained physician and via diagnostic

and laboratory tests. Most important, all medical records—from the initial admission 20 or more years ago, to the present—were reviewed.

This yielded more than 27,000 diagnoses, operations, or procedures at the 1990 assessment that occurred at some point during the postinjury lifetime of study group members. Between 1990 and 1993, another 2,636 diagnoses or procedures were recorded.

Up until 1990, the most frequently occurring diagnosis was pressure sores, with an annual incidence of 23.1 percent. Moreover, the incidence of pressure sores increased with each 10-year increase in age after age 30, but it decreased with more years postinjury. Contradictory as this appears, it seems to suggest that older individuals who had been injured shorter periods of time reported more sores than younger people injured for longer times.

Urinary tract infection with clinical symptoms was the second most frequent diagnosis, with an annual incidence of 20 percent in the years prior to 1990. Infections showed a dramatic increase in incidence among those SCI survivors who were over age 60 and a slight increase in frequency between the 10th and 30th years postinjury. There was no greater incidence of urinary infections when comparing those who had died with those still living. Between 1990 and 1993, these two leading diagnoses reversed themselves. Urinary tract infections became the most prevalent, followed by pressure sores.

While in the overall sample no other diagnosis came close to the frequency of pressure sores and urinary tract infections, there still were some patterns that emerged when study participants were grouped by injury severity, age, and duration of injury.

First, some conditions were associated with the type of neurologic injury. Persons with tetraplegia were more likely to have problems with chest infections, spasticity, perceived abdominal pain, and general malaise than those with either paraplegia or very incomplete injuries. They also had twice as many procedures to remove bladder stones or catheter-related procedures,

and they accounted for the vast majority of the many already reported urinary tract infections. Those with paraplegia, on the other hand, reported more musculoskeletal problems like joint pain and stiffness, as well as more pressure sores, diarrhea, and constipation. Those with very incomplete injuries—most of whom were ambulatory—tended to have problems with fractures, cystitis, and motor and sensory changes.

Second, there were conditions that were associated with increasing age. These included operations of the cardiac, internal, and nervous systems; pneumonia; atelectasis; respiratory infections; kidney problems; fainting; and headaches. There were also indications that pressure sores were more closely related to age than to how long the individual had been injured.

Functional decline or decreasing physical independence was an adverse outcome of long-term spinal cord injury that was documented in 22 percent of this study sample.

Finally, there were those conditions associated with the duration of the disability rather than age. These included a range of musculoskeletal problems, as well as rectal abscesses and bleeding and genitourinary problems among men.

During the 1990 data collection effort, these latter two categories were analyzed together to identify the problems in an important subgroup of study participants: those who were both the oldest and the longest injured. The people in this unique group experienced gastrointestinal conditions such as digestive system operations, diarrhea or constipation, gastric disorders, and nausea and vomiting. Genitourinary conditions such as bladder or kid-

ney stone removal, catheter procedures, pyelonephritis, or renal failure also were apparent in this subgroup. Other conditions that increased in frequency with both age and years postinjury included infectious diseases, neoplasms, motor or sensory loss, cardiovascular and respiratory conditions, and fractures and dislocations.

Finally, in the study group as a whole, while pressure sores and urinary tract infections proved to be the most frequent complications at both data collection points, there was one additional area of concern of almost equal prevalence. Though not specifically a medical diagnosis, functional decline or decreasing physical independence was an adverse outcome of long-term spinal cord injury that was documented in 22 percent of this study sample. For this particular investigation, functional decline had been defined as at least a 1-hour increase per day in the amount of assistance that was needed. Thus, the level of independence prior to the study was less important than the fact that there had been an increased need.

One-quarter of all those whose needs for help had increased blamed fatigue and weakness. Another 25 percent related this to specific medical problems. Eighteen percent identified pain and stiffness, 14 percent attributed the increased need for help to other injuries and age. Only 5 percent blamed weight gain for their needing more help—despite the fact that almost 40 percent of the 62 individuals said weight gains had made it harder for them to perform their activities of daily living.⁸

As a group, those needing more help were significantly more likely to have voiced complaints of shoulder pain, weight gain, and recent postural changes, such as scoliosis. Overall, though, it was age that was most strongly associated with the need for more help. Those who needed more assistance were an average of 6 years older than those who weren't requiring more help.⁸

For those with paraplegia, transfers to and from the wheelchair posed the biggest problem as help needs escalated.

Participants with tetraplegia, on the other hand, tended to need extra help with mobility first, then with transfers.⁸

Indications are that physical independence decreased further between 1990 and 1993. This was detected by a change in participants' scores on CHART (the *Craig Handicap Assessment and Reporting Tool*), an instrument that measures community integration in five areas: mobility, occupation, social integration, economic self-sufficiency, and physical independence.⁹ Scores also had declined in the area of social integration, which measures the extent to which individuals are socially involved and interacting with others around them.

Despite all of their medical complaints and documented diagnoses, individuals were satisfied with their lives.

General Health and Life Satisfaction

Findings that describe only increasing medical and functional complaints, however, don't tell the whole story. Despite the large number of reported complications and the presence of functional decline, many people seemingly were maintaining good health. In 1990, more than 75 percent reported feeling generally healthy. Over the following 3 years, their perceptions of their overall health actually may have improved, for when resurveyed in 1993, even more—89 percent—said they felt healthy. Their age, length of time postinjury, or neurologic status did not significantly affect these percentages one way or the other. Only one subgroup reported a worsening of general health between 1990 and 1993: those who had been injured 40 or more years.

Secondly, despite all of their medical complaints and documented diag-

noses, individuals were satisfied with their lives. In response to the most straightforward question asked—"Rate your quality of life as: very poor, poor, fair, good or excellent"—74 percent said it was either good or excellent. Moreover, there were indications that this represented an improvement over time:

- Only 56 percent imagined they would have considered their quality of life to be good or excellent 20 years ago, before the study was done.

- The number of people considering their quality of life to be poor or very poor had dropped. Twenty-four percent said they would have rated their quality of life either poor or very poor 20 years ago, while only 4 percent rated it similarly at the time the study was done in 1990. Indeed, the only study participants who said their quality of life was getting worse were people who had been hurt more than 30 years.

In general, perceived health and quality of life were related. Overall, those who reported generally good health also tended to have scored higher on the various measures of perceived quality of life, life satisfaction, and well-being, and they generally scored lower on measures of perceived stress and depression. Nonetheless, in the group as a whole, there were some decreases over time. *Life Satisfaction Index* scores,¹⁰ for example, had decreased between 1990 and 1993. Perceptions of well-being also declined slightly during the 3-year period, reflected by participants' increasing complaints of feeling bored, lonesome, and restless, as documented on the *Index of Psychological Well-being*.¹¹

Time, however, seemed to have a positive effect on stress. When queried in 1993, it was those study participants who were oldest and who were injured longest who reported the least stress, while those with the most severe disabilities or the most neurologic involvement reported the most stress. Nonetheless, as a group, the SCI participants reported less stress—particularly nervousness and feelings of being unable to cope—than their nondisabled spouses, who completed the same instrument, the *Perceived Stress Scale*,¹² in

1993. And, as reflected by scores on the *Center for Epidemiologic Studies Depression Scale*,¹³ depression scores were lowest in those who had been injured the longest. And, once again, when compared with their nondisabled partners, the SCI survivors in general reported less depressive symptoms.

Finally, in terms of their needs and priorities, as measured by the *Quality of Life and Individual Needs Questionnaire*,¹⁴ the group reported that their relationships with their families and their need for learning had grown increasingly important to them.

Tying It All Together: Identifying Risk Factors

In an attempt to predict various outcomes of long-term spinal cord injury, all of the already described data were used to develop risk models for the study sample. Working with consumers, health professionals, and other experts in the field, several outcomes—such as pressure sores, shoulder pain, or decreasing life satisfaction—were identified. For each, potential predictors of these outcomes also were identified. For example: obesity and age were examined as possible predictors for pressure sores; duration of injury, economic status, and depression were considered as some of the potential predictors of decreasing life satisfaction.

Then, in each case, findings from 1990—diagnoses, scores on the various psychosocial instruments, responses to survey questions, and other collected data—were examined with respect to specific medical, functional, and psychosocial outcomes or problems that appeared in 1993. Two regression techniques were used—logistic regression for dichotomous outcomes, such as those which measured the presence or absence of a condition, and linear regression for continuous outcomes, such as those typical of the various psychosocial instruments on which a wide range of scores were possible. Each was used, as appropriate, to predict an individual's risk of a given outcome, based on factors that were present 3 years ear-

lier. A few of the risk factors that were identified are described below:

Pressure Sores:

Several characteristics placed SCI survivors at risk for pressure sores:

- Participants with paraplegia were more likely to have pressure sores than other SCI survivors.
- Those with an existing pressure sore—anywhere and of any severity—were also more likely to have a new sore in 1993.
- Study participants with abnormal pulses in the feet and lower extremities in 1990 had a three times greater risk of pressure sores later.
- Those who did not work had more pressure sores in 1993 than those who were working in 1990.

Upper Extremity Pain

Arm and shoulder pain in 1993 also was somewhat predictable:

- Those who had lower scores on the tests for psychosocial well-being reported more upper extremity pain 3 years later.
- Previous complaints of upper extremity pain more than doubled the

chances of having upper extremity pain in 1993.

- Limitations in range of motion also more than doubled the likelihood of upper extremity pain 3 years later.

Life Satisfaction

Several characteristics predicted more satisfaction with life, as measured by the *Life Satisfaction Index*:¹¹

- Those with the highest life satisfaction in 1993 tended to be younger, had better psychological well-being, and were somewhat better off financially.
- As a group, those who reported being the most satisfied with their lives in 1993 were more involved socially in 1990, had reported less fatigue, and were less likely to be overweight.

Decreased Physical Independence

- Among paraplegics, greater age predicted declines in independence.
- Previous changes in the durable medical equipment they used were associated with less independence in 1993.
- Having an indwelling catheter, or having had to change from the bladder management program they had used

initially predicted declining function in paraplegics.

- Finally, paraplegics who had reported fatigue 3 years earlier were less able to function independently.

Fatigue

A range of symptoms and signs predicted fatigue:

- People with fatigue in 1993 were more likely to have reported fatigue in 1990 also, and they had lower blood pressure in 1990.
- Participants with poorer perceived health—those who said they did not feel generally healthy in 1990—and who had scored more poorly on psychosocial well-being tests were more likely to report fatigue in 1993

Conclusion

In conclusion, the goal of this Rehabilitation Research and Training Center on Aging with Spinal Cord Injury is to identify problems that accompany aging with a spinal cord injury, to describe their impact and their characteristics, and to explain the characteristics of those who experience them. Findings that are useful to clinicians working with aging SCI survivors can already be found in even this preliminary research. For example, this research suggests that:


- Many of the same risks nondisabled people face are equally important—or more important—for SCI survivors. The incidence of cardiovascular problems, for example, is very similar, while the risk for overuse injuries among people with spinal cord injuries may be far greater. Although these data indeed indicate that such injuries are a severe problem, they do not address the breadth of the risk—a risk that results from decades of making incredible weight-bearing demands on shoulders, elbows, and wrists.
- Certain conditions are associated more with age, others with length of injury. For example, pressure sores and respiratory problems appear to be more of an issue with increasing age. This knowledge that older individuals,



even if not long-injured, are most at risk may help clinicians intervene before problems do occur. Similarly, the finding that musculoskeletal problems are associated more with longer durations of injury than with age helps clinicians anticipate and target other needed interventions.

- Issues, characteristics, and behaviors at one point in time that predict adverse outcomes at a later point in time are vital fodder for prevention. Even those that seem obvious—such as pressure sores or upper extremity pain in 1990 predicting the same problems in 1993—tell us that these problems do not just go away on their own. Interventions or behavioral changes are needed if the ongoing cycle is to be broken.

- These research findings tell us that life satisfaction and quality of life are vital concepts. Neither is totally dependent upon the level or severity of the disability or on the number of medical complications, yet each seems to be very important as a predictor of future outcomes. Another seemingly vague concept—fatigue—appears to be an equally important predictor of future problems. Clearly, clinical complaints of fatigue—as well as depression, or decreased life satisfaction—should not go unaddressed. Unacknowledged and untreated, they may well lead to costly and compromising complications.

Finally, these findings—particularly those relating to quality of life—tell us that aging is not the entirely negative process that many people believe it to be. These data show, despite the appearance of a host of potential problems and health complications, that it is not as bad as many people imagine. Those who are in the midst of this previously unstudied process called aging with a spinal cord injury are feeling pretty good. They are happy with their lives and are glad to be alive. 

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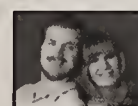
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Sexuality and Spinal Cord Injury

where we are and where we are going

Marca L. Sipski, M.D.

Maintaining a healthy sex life after spinal cord injury is an important priority to many people. Fortunately, over the past few years a large amount of research has begun to be performed in this area. Whereas in the past our knowledge about the field of spinal cord injury was exclusively focused on males and erectile function, recent work has begun to illustrate the impact of spinal cord injury on female sexuality. Moreover, recent gains in the study of infertility after spinal cord injury have allowed professionals to approach the care of newly injured patients with optimism for their potential in sexual functioning. In this article, I will provide a basic review of what is known about sexual functioning after spinal cord injury and the impact on patients.

Sexual Response

The effect of spinal cord injury on sexual response is generally discussed based upon the degree of completeness or incompleteness of the patient's injury and whether the neurologic damage affecting the individual's sacral spinal segments is an upper or lower motor neuron injury. Whether a spinal cord injury is considered complete or incomplete is determined by whether they have voluntary rectal contraction and whether they have the ability to perceive sensation around their rectum. As males have external genitalia, questionnaire studies have been utilized to determine the impact on erections and ejaculations, depending on their extent of injury. In males with complete spinal cord injuries and upper motor neuron

injuries affecting their sacral segments, there is a loss of psychogenic¹ erectile function in conjunction with maintenance of reflex¹ erectile functions (Bors & Comarr, 1960). In those males with incomplete upper motor neuron injuries, there is still maintenance of reflex function; however, some of these males may be able to have psychogenic erectile function. For those males with lower motor neuron injuries affecting their sacral spinal segments, it has been shown that approximately 25 percent of males will have psychogenic erectile function, whereas none of these males will have reflex erectile function. With incomplete lower motor neuron injuries affecting the sacral spinal segments, over 90 percent of the population will be able to have some type of erectile function.

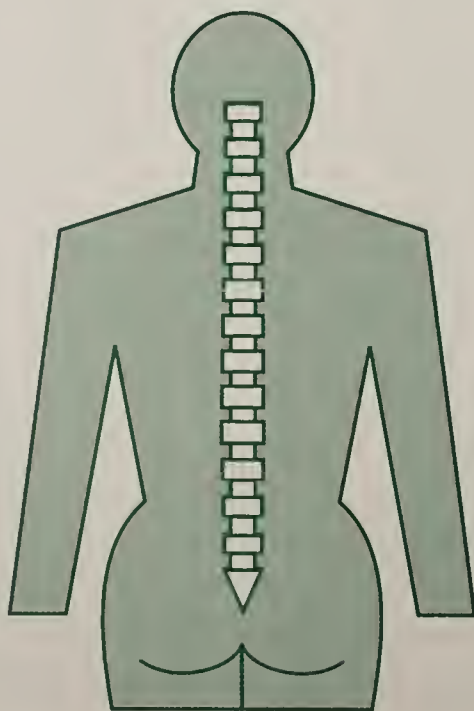
Previous reports have hypothesized that female sexual function would be affected similarly to male sexual function in that psychogenic and reflex lubrication will be maintained in a comparable

fashion to males, depending on the level and degree of the woman's spinal cord injury. Recent laboratory-based research performed at our institution has supported the hypothesis that women with complete spinal cord injuries and upper motor neuron injuries affecting the sacral spinal segments will maintain the capacity for reflex lubrication while losing the capacity for psychogenic lubrication (Sipski and Alexander, 1995a). Moreover, in those women with incomplete injuries and upper motor neuron injuries, research indicates the preservation of the ability to perceive pinprick sensation in the T11-L2 dermatomes may be able to be used as a predictor for the ability of psychogenic lubrication. Further research to confirm the effects of spinal cord injury on women with injuries below the level of T6 is planned for the future.

Ejaculatory function is markedly decreased in men with spinal cord injuries. This is most likely due to the fact that coordinated neurologic impulses from the sympathetic, parasympathetic, and somatic nervous systems are necessary for ejaculation to occur. For instance, the rate of ejaculation in men with complete upper motor neuron injuries can be as low as 4 percent (Bors and Comarr, 1960). Furthermore, many times men with spinal cord injuries have ejaculation which goes back into the bladder instead of coming out of the penis. Treatment of this inability to ejaculate has recently been used successfully to help men who suffer from infertility.

Treatment of Sexual Dysfunction

Treatment of male sexual dysfunction has been focused at the treatment of erectile dysfunction. For those males



who are able to attain reflex erections but not maintain them, the use of a silicon or rubber ring placed at the base of the penis can be helpful to maintain an erection. These rings may be used for up to 30 minutes, but should not be used on a longer basis due to the risk of insufficient blood flow to the penis causing ischemia and subsequent complications. If a male is not able to have an erection, a vacuum suction device may possibly be used effectively to produce the erection, followed by the placement of a similar ring. Again, this device should not be used for more than 30 minutes due to the risk of ischemia. Recently, FDA approval has been obtained to allow for self-administered injections of prostaglandin E1 into the penis. This is followed by an erection which occurs in approximately 5 minutes. Potential complications from prostaglandin include the development of priapism, a condition whereby an erection will not go down; therefore, emergency instructions must be available to the patient, and a system for appropriate treatment for priapism must be in place. Intraurethral insertion of medication is now also on the horizon as another mechanism to treat erectile dysfunction.

Other male sexual dysfunctions such as inability to have an orgasm, decreased sexual desire, and premature ejaculation have not been well-studied in the male population. Questionnaire studies have revealed that approximately 50 percent of males with spinal cord injuries can have orgasms and that the ability to have orgasms is not related to the degree of spinal cord injury. Furthermore, it has been documented that both sexual satisfaction and frequency of sexual activity decrease after spinal cord injury. As the focus changes from merely production of an erection to improving the quality of feeling in male sexual response, the reasons for the ability of some males to attain orgasms and others not to will need to be elucidated. Furthermore, treatment protocols for other male sexual dysfunctions will need to be developed.

Similar to male sexual functions, females with spinal cord injury have been shown to have the capacity to achieve

orgasm approximately 50 percent of the time, and this has not been found to be related to the degree of injury. This has also recently been confirmed via laboratory-based research (Sipski & Alexander, 1995b). Similar to males, women with spinal cord injury have been shown to have decreased sexual satisfaction in addition to decreased frequency of sexual activities postspinal cord injury. Treatment of inability to have orgasms, decreased sexual desire, and arousal disorders has not been attempted in a standardized fashion in women after spinal cord injury. Because some women with spinal cord injury may be able to be orgasmic, the use of sex therapy techniques similar to those utilized in the nondisabled population may be an appropriate treatment in the future for women with spinal cord injuries.

For those women who become pregnant after spinal cord injury, it is important that their gynecologist is aware of the potential complications associated with pregnancy and spinal cord injuries.

Treatment of Male Infertility

As ejaculation is greatly decreased after spinal cord injury, it follows that infertility can become a problem (Sipski & Alexander, 1992). In addition to the inability to ejaculate, males with spinal cord injury have decrease in the quality and quantity of sperm which occur in the first few weeks postinjuries. Production of ejaculation via electroejaculation (electrical stimulation in the area of the prostate which produces ejaculate) followed by either

- in utero insemination (insertion of the semen in the woman's uterus),
- in vitro fertilization,² or
- intracytoplasmic sperm injection³


has emerged as a viable option for treatment of male infertility after spinal cord injuries. Whereas the use of these

techniques has been able to produce pregnancies in the partners of men with spinal cord injuries, these techniques must be performed in a clinic setting and can be somewhat costly. An alternative method to remediate male infertility has been the use of electrovibration applied to the penis. Due to the risk of autonomic dysreflexia,⁴ this technique is initially performed in a clinic setting, but may also be performed at home, and has been done so in Europe and other countries around the world. Electrovibration, similar to electroejaculation, is coupled with artificial insemination of the female.

Women with spinal cord injuries suffer from temporary loss of their menstrual periods after their injuries. After this, there is generally resumption of periods, which most times return similar to their previous fashion. Menstrual pain is still present after spinal cord injury and there is generally not a decrease in the ability of a woman with a spinal cord injury to conceive. For this reason, the need to use birth control must be emphasized with women who have spinal cord injuries.

For those women who become pregnant after spinal cord injury, it is important that their gynecologist is aware of the potential complications associated with pregnancy and spinal cord injuries. These can include anemia, problems with transfers due to weight gain, urinary tract infections, pressure sores, and, most significantly, autonomic dysreflexia, which frequently occurs during labor in women with injuries above the level of T6. Unfortunately, confusion of autonomic dysreflexia with preeclampsia⁵ still occurs and the gynecologist who works with a woman with spinal cord injury must be able to differentiate between these two conditions in order to properly treat dysreflexia in the woman with spinal cord injury. Some studies have shown an increased risk of caesarean section in women with spinal cord injuries; however, more recent works have not shown this increased incidence.

Conclusion

Sexual activity and the ability to remain a sexual being persists in both males and females after spinal cord injuries. As such, it is important to provide the patient with information about how their sexual response and sexual functioning can be affected after spinal cord injuries and for healthcare professionals to know where to refer patients who are in need of further information. In our rehabilitation hospital, this information is supplemented by the presentation of our patient education video, "Sexuality Reborn" (Alexander & Sipski, 1993). The video includes various couples speaking about their sexual functioning after spinal cord injury and demonstrating various sexual techniques. Building upon these two instructional presentations, the patient may also be referred to a sexuality clinic for further information about their sexual potential or remediation of problems which may occur. It is important that in this time of change in the healthcare system, the need to maintain healthy sexuality in persons with spinal cord injury not be ignored. Recent advances in our understanding of this area can be utilized to educate and counsel patients and optimize their level of sexual health. 

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2. With *in vitro* fertilization, the male's sperm and the female's egg are put together outside of the woman's body. After the sperm fertilize the eggs the embryos are placed into the women's uterus.
3. With *intracytoplasmic sperm injection*, an individual sperm is used to fertilize an individual egg outside of the woman's body. The embryo is then placed in the woman's uterus.
4. *Autonomic dysreflexia* is an abnormal reflex which occurs in people with spinal cord injuries at the level of T6 and above. A noxious stimulus such as bladder distention causes a chain of reflexes which can lead to dangerously elevated blood pressure, sweating, headache, and other symptoms. The condition is treated by removing the offending stimulus and giving the patient medication.
5. *Preeclampsia* is a medical condition which results in hypertension and can result in seizures which can occur during pregnancy.

Notes

1. In the able-bodied male there are two pathways for erection, both of which result in increased engorgement of blood in the penis. With a *psychogenic* erection, the person is aroused in his brain by seeing something or hearing something. With a *reflex* erection, the person is aroused by touching in the genital region/area.

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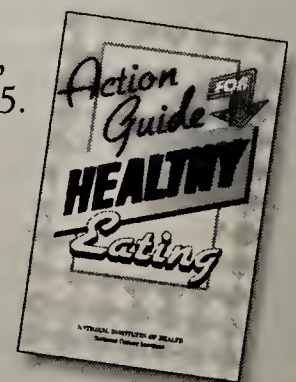
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New HKNC Awareness Campaign:

In the Dark About People Who are Deaf-Blind?

Share Helen Keller's Vision by participating with agencies and organizations worldwide in the Helen Keller National Center's 1997 Awareness Campaign which focuses on "independence" and the participation of people who are deaf-blind in their communities—at school, in the workplace, and at home.

Most people who are considered deaf-blind are not totally blind and totally deaf. There is tremendous variety in the degrees of vision and hearing loss, and a great range of individual abilities and needs among this population—estimated at more than 70,000 Americans. This figure excludes the escalating number of older adults who are losing vision and hearing, due to the aging process, who strongly desire to retain their independence. Today, many "fragile" premature babies are surviving due to advanced technology, but often have vision and/or hearing impairments. Recent statistics indicate that there are nearly 11,000 young people, ranging from infants to age 21, who are deaf-blind, and that number is growing.

According to Dr. Robert J. Smithdas, assistant director at the Helen Keller National Center, who has been deaf-blind since the age of 4 ½, "Independent living means an ability to function smoothly and easily within the structure of society, being able to communicate with others to obtain useful information, travel freely and without fear, and have the ability to perform chores that are necessary for survival."

During the last 25 years, much progress has been made in providing education and specialized vocational rehabilitation training. Today, people with dual sensory disabilities have options, make choices and express preferences. Individuals may live in their own homes, in a shared apartment, or in a group home with support staff. Aids and devices such as low vision clocks, tactual wake-up devices, tactile signal alerting systems, large print and braille telephone devices make independent living feasible. However, sufficient and appropriate residential sites remain a critical need.

People work in jobs ranging from food service at a local hospital or restaurant to data entry at AVIS, stock clerk in "the GAP," and teaching at a technical college. Some folks use public transportation—buses, trains, or taxis—and can travel comfortably to work, visit families, or shop in town. Others may need someone to accompany them. Communication, the key to learning, knowledge, and access to people, varies—from the use of voice, tactile sign language, and writing in large letters on the palm of a person who is deaf-blind to the use of portable braille devices like the Braille Lite. Individuals with limited language skills may use a communication

book which could have pictures, tactile graphics, and printed words to indicate what the deaf-blind person wants.

Pictured in the 1997 awareness poster and public service ads are Sandra and Scott Stoffel. Deaf as a young child, Sandra started to lose her vision at age 21. She discovered that she had Usher syndrome, a genetic condition combining hearing loss and Retinitis Pigmentosa (RP), a major cause of deaf-blindness. Afraid to attend college and pursue her interest in nursing, she stopped planning for her future. After enrolling in a rehabilitation training program, she soon acquired the skills she needed to regain her independence. She met a fellow student, Scott, who was diagnosed with "Stoffel syndrome," a neuro-muscular disorder. He was legally blind and had experienced a severe hearing loss at age 18. Friendship blossomed into love and they married in July 1996. Today they live in an apartment on a large university campus where Scott is majoring in computer science and creative writing. Sandy is working towards a certificate program in medical transcription at a nearby college. Both are following their preferred interests, using their talents and facing the joys and problems of everyday life.

Originally proclaimed by Congressional resolutions and Presidential signature 11 years ago, awareness activities and events featuring information about significant vision and hearing loss, or deaf-blindness, now occur throughout the year, beginning in June, the month of Helen Keller's birth.

All citizens, health organizations, civic groups, libraries, schools, and agencies are encouraged to plan state and local activities during the month of June, and especially during the week of June 22–28. A sample proclamation, a radio public service script, list of suggested activities, 1997 poster, ad slicks, and this press release are available at no cost from the Public Relations Department, Helen Keller National Center, 111 Middle Neck Road, Sands Point, NY 11050, or by calling Barbara Hausman, (516) 944-8900, ext. 325 (voice), 516-944-8637 (TTY), or 516-944-7302 (fax).

The Helen Keller National Center is the ONLY national program which provides diagnostic evaluation, short-term comprehensive vocational rehabilitation, and assistance with jobs and residential placement for all Americans who are deaf-blind. Local services and training are offered nationwide to these individuals, their parents, and professionals in the field through the center's 10 regional offices, some 40 affiliated agencies, a National Training Team, Older Adult Program, National Technical Assistance Consortium for Children & Young Adults Who Are Deaf-Blind (NTAC) and D-B Link. The center partially funds a National Family Association for Deaf-Blind.

Allsup Inc. Launches Home Page for Disabled Persons

Allsup Inc. recently joined the worldwide community of Internet users with the launch of a website directed to the nation's disabled. The address is <http://www.allsupinc.com>

For the first time, potential Social Security disability claimants can prequalify for Allsup representation by completing a simple online screening questionnaire. After qualifying, prospective claimants can download, print out, and complete Social Security Administration form SSA-1696, appointing Allsup Inc. as their representative to begin the process of qualifying for benefits. The SSA requires that a hard copy of this form be completed and mailed to Allsup Inc.

The advantage of online qualification is speed.

Allsup already reduces the time it takes to file for Social Security disability benefits by more than a month because all medical and financial information is compiled within 3 days of initial contact. By initiating the paperwork online, Allsup officials expect to shorten the process even more.

Claimants who rely on Social Security to handle their cases usually wait at least 2 months for their initial file to be completed.

The Allsup website also gives computer users the most comprehensive and up-to-date information on disability, representational services, Congressional reengineering, and other initiatives that can affect their benefits.

Georgia Bartels, national products manager for Allsup, said Social Security maintains its own home page, but it often contains difficult to understand bureaucratic language.

"Individuals want to know all of the options available if they become disabled and where their income will come from," Ms. Bartels said. "The Allsup website will be a readily available research tool with information they can understand."

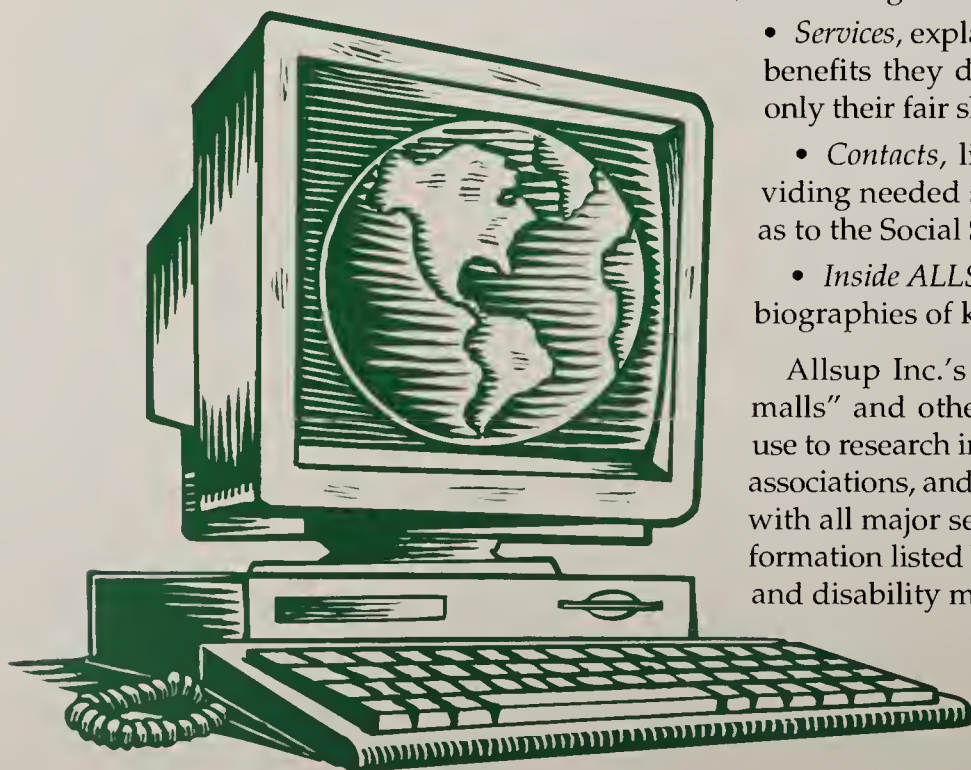
Allsup's home page also provides invaluable information to company benefits managers responsible for their disabled workers.

Included in the page are the following features:

- *News*, concerning Social Security, Medicare, and legislative issues;
- *Services*, explaining how Allsup helps individuals obtain the benefits they deserve and how Allsup helps companies pay only their fair share of disability benefits;
- *Contacts*, links to numerous disability associations providing needed services to Americans with disabilities as well as to the Social Security Administration; and
- *Inside ALLSUP*, providing details about the company and biographies of key personnel.

Allsup Inc.'s website address will be listed in "disability malls" and other Internet sites that persons with disabilities use to research information on special services, support groups, associations, and newsletters. The address also will be registered with all major search engines that allow "browsers" to find information listed by categories, such as disability, Social Security, and disability management.

Allsup Inc., based in St. Louis, is the first and largest national company representing disabled individuals before the Social Security Administration.



NEW PUBLICATIONS AND FILMS

The Performance of Healing.

Carol Laderman and Marina Roseman, editors. Routledge, 7625 Empire Dr., Florence, KY 41042. Softcover, 330 pages. \$18.95.

This text is a collection of essays by anthropologists covering a wide range of medical, holistic, and religious aspects of healing and death. The contributors broaden the field of medical anthropology by demonstrating that healing involves the senses in treatments whose efficacy depends in part on dramatic performance.

Music, movement, and dialogue; comedy and poetry; audience, players, and props—all constitute the performance of healing. If healing is to be effective, the patient's body and mind must be engaged through the sensory impact of dramatic media, the articles show. Curing is not just about "making people well," but also forms a crucial means of reproducing relations of power. A performance directed toward a particular individual might also heal a traumatized social group, expanding the definition of "cure" from its narrow sense of restoring a victim to health to the larger goal of restoring social relations.

The Romance of American Psychology. Political Culture in the Age of Experts.

Ellen Herman. University of California Press, 2120 Berkeley Way, Berkeley, CA 94720 and/or 50 East 42nd Street, Room 513, New York, NY 10017. Hardcover, 419 pages. \$35.

A quiet academic discipline two generations ago, psychology has become a voice of great cultural authority. From family structure to government policy, child abuse to urban violence, few social institutions or political issues in America remain untouched by the wisdom of psychological "experts."

Attempting to fully explore the political and cultural significance of American psychology in the post-World War II era, the author tells the story of this country's love affair with the behavioral sciences.

Mental Health in a Multi-ethnic Society. A Multi-disciplinary Handbook.

Suman Fernando, editor. Routledge, 7625 Empire Dr., Florence, KY 41042. Softcover, 235 pages. \$18.95.

As services in the community continue to replace institution-based care there is an increasing need for professionals from medical, social work, clinical psychology, nursing, and other backgrounds to address the diverse needs of a multi-ethnic society using a common frame of reference. Those who provide mental health services must now face up to challenges from service users and strive for a closer, more effective working relationship with voluntary organizations. This book attempts to address all these issues. It offers an approach to the meaning of mental health and suggests constructive and imaginative ways of providing care for people with mental health problems.

Contributions from a multi-ethnic team of professionals are organized in three parts: "Current setting" describes the background to contemporary mental health services, the legal framework, and the role of the voluntary sector and examines the experience of black people. "Confronting issues" considers practical problems in delivering services to a multi-ethnic society and offers some innovative approaches. The final part, "Seeking change," draws together the various issues in order to indicate a way forward, with suggestions for change on both a practical and theoretical level.

Intended primarily as a handbook for practitioners working in the mental health field, it is also suitable for multidisciplinary, basic, and in-service postgraduate trainings in a variety of professions, including social work, psychology, psychiatry, and nursing.

Occupational and Physical Therapy in Educational Environments.

Irene R. McEwen, editor. The Haworth Medical Press, 10 Alice Street, Binghamton, NY 13904-1580. Hardcover, 110 pages. \$29.95.

Covers the major issues involved in providing lawful, team-oriented, and effective occupational and physical therapy services for students with disabilities in public schools. For those involved with students with disabilities, this book helps them make sound decisions about services that will make a meaningful difference in the lives of these children.

Since the 1975 enactment of Public Law 94-142, which mandated that occupational and physical therapy be provided "as may be required by a handicapped child to benefit from special education," this required link between therapy and education has continued to lead to confusion and controversy about which students should receive therapy in school and what types of services should be provided. The purpose of this text is to clarify the major issues surrounding occupational and physical therapy in public schools and to provide a framework for delivery of team and family oriented services that meet individual needs of students with disabilities.

This book should be useful for occupational and physical therapists who work in public schools, school administrators, teachers, and parents of disabled children.

**Communication Therapy
An Integrated Approach to Aural
Communication**

Mary June Moseley and Scott J. Bally, editors. Gallaudet University Press, 800 Florida Ave., NE, Washington, DC 20002. Toll-free number: 1-800-451-1073 (V/TDD), Hardcover, 344 pages, \$59.95.

Depending upon when and to what extent an individual has experienced hearing loss, enhancing his or her communication skills can present a wide range of different challenges. This book emphasizes a functional approach to aural rehabilitation developed and refined during the past several years specifically for students and professionals. It details the use of an integrated therapy strategy designed to meet a variety of client needs while simultaneously working on multiple communication skill areas.

**Sexuality After Spinal Cord Injury.
Answers to Your Questions.**

Stanley H. Ducharme and Kathleen M. Gill. Brookes Publishing Company, The Maple Press Distribution Center, I-83 Industrial Park POB 15100, York, PA 17405. Softcover, 244 pages, \$22.

Anatomy, fertility, sexually transmitted diseases, self-esteem, sexual satisfaction, and parenting are some of the topics included in this volume, which attempts to deliver honest answers to urgent questions on the subject of sexuality and spinal cord injury (SCI). It draws heavily on the experiences of men and women living with SCI for the authors to relay practical information acknowledging different lifestyles, tastes, values, and orientations.

**Directory of Education Grants.
First Edition.**

Research Grant Guides, Inc., Dept. 3A, P.O. Box 1214, Loxahatchee, FL 33470. Telephone: (561) 795-6129. Fax: (561) 795-7794. \$59.50, plus \$6.00 for shipping and handling.

This directory identifies 650 qualified foundations awarding education grants to all types of nonprofits. The state-by-state arrangement allows the reader to

target only those sources awarding grants in his/her geographic area. The following categories are included: adult education, cultural education, disabled, elementary education, health education, higher education, libraries, literacy, medical education, minorities, religious education, scholarships/financial aid, science/mathematics, secondary education, and special education.

**Living in the State of Stuck.
How Technology Impacts the Lives
of People with Disabilities.
Second Edition.**

Marcia J. Scherer. Brookline Books, P.O. Box 1047, Cambridge, MA 02238-1047. Telephone: (617) 868-0360. Fax: (617) 868-1772. Softcover, 181 pages. \$17.95.

The author describes assistive devices that enhance the quality of the lives of disabled persons, their mobility, speech, and ability to work. He further shows how, paradoxically, "the more technology became available and the more free from limitations individuals became, the more stuck they seemed." He goes on to explain how friends and relatives can better understand the personal issues and needs that arise from living with a disability and "needing" these devices.

Alcohol Problems in the Community.

Larry Harrison, editor. Routledge, 29 West 35th Street, New York, NY 10001-2299. Telephone: (212) 244-3336. Fax: (212) 564-7854. Hardcover, \$59.95 (U.S.) and \$83.95 (Canada); softcover, 275 pages, \$19.95 (U.S.) and \$27.95 (Canada).

This book examines the wide range of difficulties that vulnerable people experience in relation to drinking. The first part of the book begins with a report on recent U.S. research on the role of alcohol in the perpetration of child abuse and recent research on young people's drinking problems. This is followed by a study on the prevalence of drinking problems among older people which, the authors argue, has been underestimated. In the second half of the book, empirical evidence is presented on the particular difficulties faced by ethnic, migrant, and homeless groups and this emphasis on

the centrality of social disadvantage leads on to a consideration of a specific social work role in the assessment and management of alcohol-related problems.

**Clinical Bulletin of Myofascial
Therapy: The practical journal for
the soft-tissue practitioner.**

John C. Lowe, editor. The Haworth Medical Press, 10 Alice Street, Binghamton, NY 13904-1580. Quarterly. Subscription rates: individuals, \$36; institutions, \$48; and libraries, \$105.

Like its predecessor, the *Journal of Myofascial Therapy*, the peer-reviewed *Clinical Bulletin of Myofascial Therapy* is directed towards doctors and therapists in active clinical practice. Its main purpose is to publish clinically useful information on myofascial therapy, which the editor defines as: "any technique or procedure that may relieve or prevent pain, dysfunction, or other signs or symptoms of abnormality related to the myofascial tissues of the body."

Who's Fit to be a Parent?

Mukti Jain Campion. Routledge, 29 West 35th Street, New York, NY 10001-2299. Telephone: (212) 244-3336. Fax: (212) 564-7854. Softcover, 311 pages, \$19.95; hardcover, \$62.95.

Who's Fit to be Parent conducts a thorough investigation into how society currently judges parents by looking at the professionals who assess parenting and by examining the charges made against certain "unfit" groups who are, nonetheless, becoming more widespread as parents—for example, those who are single, gay, disabled, or drug-addicted. It brings together professional and academic research which challenges traditional views of how to assess parenting with the personal experiences of a wide range of "nonconventional" families. Chapters in this book include those on disabled parents, mentally handicapped parents, drug addicted mothers, gay parents, teenage mothers, older mothers, single mothers, lone fathers, working mothers, and black parents.

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Reengineering Rehabilitation in the Texas Rehabilitation Commission

Jackie Feinberg

On June 2, 1997, the 513 counselors of the Texas Rehabilitation Commission (TRC) awoke to find a totally redesigned-from-the-ground-up system for providing services to some 100,000 clients annually. Over 3 years in the making, the new system—dubbed *Rehabsys*—represents a sweeping breakthrough in computerizing and streamlining the provision of VR services.

The Charge

The TRC initiative was in line with the *Aspen Document*, issued in 1993 by state VR directors, in cooperation with the Council of State Administrators of Vocational Rehabilitation (CSAVR). The document outlined steps to:

- identify practices and policies impeding rehabilitation outcomes;
- simplify “process” requirements, and focus on quality employment outcomes;
- use existing data for the determination of eligibility;
- document only information essential to achieving outcomes or required by law; and
- reduce statuses to eligibility, services, and outcomes.

On the need to streamline, TRC Commissioner Max Arrell maintains that we must keep the integrity of the VR program intact. The mission of what we do is still valid and the commissioner will continue to fight for it, but the way we do business must change. The process must change.

The Results—An Overview

Outcome driven, *Rehabsys* does the following:

- It increases client involvement.
- It encourages a team approach by the counselor and direct support staff.
- It broadens communication and consultation so that the client benefits from all of TRC’s available resources.
- It encourages a comprehensive approach.
- It allows counselors more time with clients, less time pushing paper.
- It increases information available about employer needs and job demands for specific geographic areas.
- It allows counselors to offer more employment options to clients.
- It provides automated checks and balances that reduce approvals, errors, and handoffs.
- It integrates rehabilitation services and procurement processes.
- It eliminates need for repeated re-keying of data on forms, etc.
- It offers a pulldown English language list to select just about everything: specifications of services and goods, vocational objectives, disability information, providers, demographics, and more.

The system’s goal is “Work smarter, not harder.” Once basic client information is in the system, *Rehabsys* then does the once labor-intensive, repetitive tasks at the click of a mouse. Clerical staff now have more time to assist the counselor with direct service support.

Electronic Case File

Counselors access an electronic case file—application (profile), Individualized Written Rehabilitation Program (IWRP), eligibility statement, and counselor notes—via a Pentium-class computer and local area and statewide networks (LAN’s and WAN’s). The counselor maintains paper documents only if required by law or received from outside sources such as medical records and invoices.

Instead of re-keying data repetitively in the preparation of separate paper applications for vocational rehabilitation, independent living services, comprehensive rehabilitation services, and extended rehabilitation services, the counselor now uses an electronic “profile,” which captures information once-

Figure 1. Highlights-Texas Rehabilitation Commission Vocational Rehabilitation Program

- Statewide, there are 464 counselors in 143 field offices within 5 regions.
- 104,301 persons with disabilities applied for services.
- Of the 92,009 eligible clients, 22,188 were successfully rehabilitated and 51,700 continued to receive services at the end of the year.
- TRC served 9.3% of the potentially eligible population of Texans with disabilities.
- 70% (15,531) of the clients rehabilitated in FY 1995 had severe disabilities.

Source: TRC 1996 Annual Report.

only at the beginning and then throughout the life of the case.

Rehabsys has achieved significant savings in counselor time by transforming the 16 client statuses into 4 phases:

1. *Intake*: initial contact, profile, and eligibility determination.
2. *Plan Development*: comprehensive assessment, explore outcomes, develop services, and develop IWRP.
3. *Service Provision*: implement services and monitor and evaluate service/access outcomes.
4. *Closure*.

The phase of "Plan Development" which was not part of the original *Aspen Document* evolved due to its importance to a successful outcome and efficient quality services, its connection to client involvement, and the amount of effort and time required to complete this phase.

Action List

An automated action list helps the counselor manage time more productively by giving timely reminders for different actions that need to happen in a client's plan. The action list increases the role of the rehabilitation services technician (RST) as a partner in the service delivery system and allows the counselor time to market the employment of persons with disabilities to employers.

The action list "Due Dates" are either system-generated by previous actions or initiated by a counselor or RST setting up a specific reminder. Due Dates say to the counselor: "Your attention is due." Actions are no more than a tug on the sleeve or a whispered reminder (see Figure 2).

The action list also encourages communication among staff, as any TRC employee can access the list. For example, the operator can delegate actions, and the list of actions then can be accessed by area manager, counselor, employee name, and caseload. This team approach expedites and fosters quality services.

Regardless of who an action is delegated to, the action is displayed on the



RST Robin Sharp and Eldon Mickler, counselor, test Rehabsys in the East Austin field office.

case or caseload list. The operator can access all actions, or narrow the search by selecting a specific action type such as:

- followup/review actions to follow up on a treatment source or conduct an annual joint review,
- payment actions to pay for a received good or service, or
- purchase order actions to verify receipt of a good or service.

The *Service Record* is a new step in TRC's rehabilitation process. It is the collection of information for planning and it integrates the rehabilitation and purchasing process. The information collected about planned purchases is used to create the IWRP and later to generate the purchase order. It consumes time early in the process. But the payoff makes it worthwhile, as follows:

- Information is entered once—no rekeying and fewer errors.
- Time spent up front is saved later by allowing the creation of the purchase order or payment for the purchase with the click of a button.
- It provides a planning tool for the client and counselor.
- It increases the information available to the client for an informed choice.
- The system itself edits facts and figures according to law and policy, so there is confidence that purchasing can

be handled at the lowest level, thus speeding services to clients.

Purchasing

Driven by "best value" rather than "lowest cost," the client purchasing process gives more purchasing power to counselors and RST's and more flexibility in choices to clients.

Counselors and clients have immediate access to information on services and providers, including detailed specifications of goods and services, past performance of providers, costs of services, and other necessary information to make an informed choice.

The following six easy steps to purchasing (with computer-generated purchase order and payment) allow central accountability while increasing choices for the end user:

- Look up the goods or service specification.
- Either select it or custom build what you want using the template.
- Select a provider.
- Watch the computer automatically create the purchase order.

Ms. Feinberg is Business Systems Project Manager for the Texas Rehabilitation Commission.

Figure 2. Examples of System Generated Actions

During . . .	this activity . . .	triggers an action reminder . . .
Intake/Profile	<p>The scheduling of an appointment for a client</p> <p>The assignment to a counselor</p> <p>A signed application statement event</p> <p>The generation of a "Request for Information" from a treatment source</p> <p>The placement of a case in extended evaluation</p> <p>Updating information on the Profile or Financial screen</p>	<p>to notify the assigned counselor of the appointment.</p> <p>to notify the counselor of the assignment.</p> <p>to the counselor to determine eligibility.</p> <p>to the counselor to follow up.</p> <p>to the counselor for determination.</p> <p>that states "Financial or Initial contact information is updated."</p>
Plan Development	<p>The signing of an IWRP, or IWRP amendment</p> <p>The entry of a next contact date on the case note window</p> <p>The creation of a service record</p> <p>The generation of a purchase order</p> <p>The acknowledgment of receipt of goods and invoice</p> <p>The attempted issue of a purchase order that requires area manager approval</p> <p>The approval, or not, by the area manager of a purchase order</p> <p>The transfer of a case</p>	<p>to the counselor to conduct an Annual Review.</p> <p>to the counselor for a contact due.</p> <p>that a purchase order is needed.</p> <p>to verify the receipt of goods/services and invoice (delivery is due).</p> <p>that a pay authorization is needed.</p> <p>to the area manager that an approval is needed.</p> <p>to the counselor to take the next action.</p> <p>to the receiving counselor and the transferring counselor.</p>
Closure	<p>The entry of "hire date" on the employment window</p> <p>The closing of a case as ineligible for selected reasons</p> <p>The successful closure of a case where work status is "sheltered employment"</p>	<p>to the counselor that a closure is due.</p> <p>to the counselor to conduct an Annual Review.</p> <p>to the counselor to conduct an Annual Review.</p>

Figure 3. Examples of Due Dates for System Generated Actions

The system generates an action when you save the . . .	with . . .	to . . .
profile	21 days before deadline (60 days after the application date)	determine eligibility.
IWRP	30 days before the IWRP anniversary date	conduct a joint annual review.
service record	10 days before the start date	generate the purchase order.
authorization for payment for maintenance and transportation	7 days before the start date	authorize the next payment.

Note: Due dates for system generated actions vary depending on the action due.

Figure 4. Reengineering Phases at TRC

Phase	Period	Included	Participants
Information Gathering	January to June 1994	<ul style="list-style-type: none"> • visits to field offices • business process flow diagrams of the current system • collection of rules applied to current system • review of other streamlining efforts and tools to support streamlining 	<ul style="list-style-type: none"> • counselors • rehabilitation support specialist (RST's—counselor, direct support staff) • managers • clients • providers • technical and ancillary process support staff such as Automated Services, Financial Services, Administrative Services
Conceptual Designs	July to October 1994	<ul style="list-style-type: none"> • process concept, outline, and high level design • process rules • impact on stakeholders; values and beliefs; roles, skills, and location; staffing 	<ul style="list-style-type: none"> • two task groups: <ul style="list-style-type: none"> ▼ Rehabilitation Services and ▼ Procurement/Payment, comprised of: <ul style="list-style-type: none"> – counselors – RST's – area managers – rehabilitation program specialist – clients
Detailed Designs	November 1994 to April 1995	<ul style="list-style-type: none"> • process definition (detailed description of who, what how, when) • data definition of information coming in and going out of each activity • description of controls • measurement analysis 	<ul style="list-style-type: none"> • two labs: <ul style="list-style-type: none"> ▼ Rehabilitation Services and ▼ Procurement/Payment, comprised of: <ul style="list-style-type: none"> – counselors – RST's – area managers – rehabilitation program specialist – technical support, such as Automated Services, Financial Services, Administrative Services • subgroups comprised of subject matter experts
Implementation	May 1995 to June 1997	<ul style="list-style-type: none"> • development, testing, training (including practicing) • automated tools • on-line policy/procedure manual • training materials 	<p><i>Testing</i></p> <ul style="list-style-type: none"> • two test groups <ul style="list-style-type: none"> ▼ various end users from all over the state (4 weeks) ▼ one field office (9 months) <p><i>Training</i></p> <ul style="list-style-type: none"> • class room setting <ul style="list-style-type: none"> ▼ all field staff ▼ managers ▼ medical services coordinators ▼ support staff (such as help desk, program specialist, and Buyer Support Unit.) • practice lessons for all field staff

- Enter the dates the invoice and the goods or services are received.

- Watch the computer automatically create the voucher to pay the provider.

An automated vocational exploration tool, called *Choices*, gives counselors and clients quick access to information that links a client's interest and aptitudes to specific jobs; reasons why certain jobs aren't appropriate; and information on colleges, trade schools, and more.

Information about job vacancies is available to counselors on their computers through an agreement with the state employment commission.

Other information tools include:

- online hypertext policy manuals,
- online medical references, such as *The Physician's Desk Reference*, the *Merck Manual* and *Stedman's*,
- hot lists (or favorites) of Internet databases for job postings, financial aid, and more about the entire state or a specific locality, and
- automated help screens and micro help (prompts at the bottom of each screen for each entry field).

Rehabsys makes instantly available to managers and other staffers enormous databases of client, purchasing and budget information.

Management Information System

Rehabsys makes instantly available to managers and other staffers enormous databases of client, purchasing and budget information. As Area Manager Dwight Lindsley explained, "I can't tell you how worklife will be different with the new MIS [management

information system] until I've used it for 6 months, but I can tell you that with the anticipated features it will improve life. I can look at just about anything in a case file without getting out of my chair."

Mr. Lindsley and other managers now can obtain up-to-the-minute information on a case-by-case basis; end-of-day information in standard formats on our Intranet or through a data warehouse application (this includes performance statistics that "drill down" from statewide to regional to unit to counselor); answers to ad hoc inquiries according to parameters such as counselor number and time period.

The new focuses of the area manager (supervisor of counselors) and management audit case reviews, rather than on detailed processes, are on outcome and essential statutory requirements. Utilizing a "best practices" approach, there is the same flexibility in audit procedures as in the service delivery system.

In the Beginning...

In 1994, the Reengineering Implementation Steering Committee (RISC)—led by the commissioner and the top executives of the agency—was established to make decisions and provide direction and momentum. A project planner was assigned to keep management informed and coordinate multiple overlapping initiatives, making sure it all fit together.

TRC looked at VR from every angle, based on three simple criteria:

- get people into services quicker;
- serve them more efficiently; and
- help more of them go to work.

Beginning in 1994, field staff, providers, clients, and administrative support staff began work, focusing on the redesign of a service delivery system responsive to clients' needs (see Figure 4). After 3 years of development, including thorough testing by end-users and training of field staff, the new system was implemented June 2, 1997.

The Future

A cross-functional user group has been formed to look at proposed improvements to the system. Each proposal will be reviewed by the group to determine:

- its *validity*—whether it is the right solution and not a personal preference, quick fix, Band-Aid, or answer off the top of someone's head;
- its *completeness*—whether the description provides the specifications needed to begin development; and
- its *value*—a measure of the merit, desirability, usefulness, or importance this improvement adds to services.

The improvement is scheduled as a priority if the change is due to a new law or is expected to have a major impact on services, staff is available (not tied down by other major initiatives) or the work can be contracted outside the agency, if the change is not too time consuming, and if it is relatively easy and related to a change that is at the top of the list.


With our new automated environment, TRC has the opportunity to make changes to its case management application more often. For example:

Fix on the Fly. Open systems (LAN and WAN) allow TRC to fix many operational problems without disrupting day-to-day business.

New Releases. Plans include new releases (such as 2.0, 3.0 and so on) in October 1997 and April 1998. If needed, there will be upgrades in between (such as 2.1, 2.2, or 3.1).

A Way of Life

The reengineering project created a new era for Rehabilitation Services in Texas—one that will truly take TRC into the new century. The project has come a long way, but work will continue as TRC looks at ways to improve services and add enhancements to its automated system.

Implementation is not the end, but the beginning. With new philosophies and tools, TRC is changing its culture. There is a new commitment to the business TRC is in and in assuring that it is the best it can be. 

Streamlining: Moving Beyond the Quick Fix



On the job with Wayne Taylor, student worker, are Angie Williams (left), special education teacher at Thomson High School and coordinator of community based education, and Barbara Hughes, DRS vocational counselor.

James E. Stephens

Streamlining is but one response of private and public sector organizations to what has been called the challenge of the three C's: customers, competition, and change (Hammer & Champy, 1993). Beginning in the early 1980's, American society has seen a shift in the fundamental relationship between sellers and buyers in the private sector and service providers and consumers in the public sector, with this shift having a profound effect in most of the western democracies.

Consumers of goods and services, including public services, now tell suppliers what they want, when they want it, and what they are willing to pay. In the public program of rehabilitation, laws have been passed which affect all

phases of the traditional rehabilitation service delivery process, including some aspects of consumer choice, timeliness, and service quality. Consumers of public rehabilitation services have demanded and been granted unprecedented levels of participation and control in making decisions which ultimately affect expected outcomes.

Competition between and among producers and suppliers in the private sector has been the hallmark of the American free enterprise system. However, public sector goods and services have traditionally been seen as immune from the vagaries of private sector market forces. This difference may no longer be as apparent in the late 20th century. Competition among providers and suppliers in the rehabilitation marketplace is fierce and will only intensify.

As resources become more scarce, efforts to find comprehensive solutions to very complex problems will accelerate. Among those solutions will be attempts to privatize public services, downsize government, and find faster and better ways to produce needed services. Streamlining has been among a myriad of methods introduced in an attempt to improve efficiencies in the public sector.

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Change is the third and most pervasive of the three C's. Little reminder is needed of the tremendous changes in society in general and public and private organizations in specific that have come about as a result of the vast technological and information revolution sweeping the world. Most members of American society have instant access to a wide variety of information which not only informs but creates a level of receptivity to market segmentation never before achieved. Accessing goods and services more quickly, when they are desired and where they are desired, is no longer a wish but an expectancy.

Against this complex backdrop of fundamental change, streamlining has emerged in the public program of vocational rehabilitation as one response to a complex set of circumstances.

Early Efforts

Efforts to incorporate streamlining techniques for change in state rehabilitation agencies is not new. In 1981, the Georgia Division of Rehabilitation Services and the Management Control Project (MCP) at the University of Georgia began a collaborative effort to significantly streamline the existing state agency rehabilitation process (Field, 1981). The rationale for developing the MCP effort, remarkably similar to that supporting the current effort, included:

- a belief that the system was somewhat dysfunctional due to the layering of controls,
- a history of more and more controls added to ensure that workers were complying with federal guidelines,
- a supervisory staff performing primarily monitoring activities rather than supporting the best efforts of service delivery staff, and
- a growing awareness that major constituents, including consumers, wanted to take a more active role in shaping the program.

It is notable that the Georgia rehabilitation agency, though having gone through many permutations of streamlining-like activities since 1981, is currently undergoing a major metamorphosis that includes significant changes

in organizational structure, mission focus, service provider and management roles, and major markets. This attempted transformation can be seen as a part of a two decade long effort to improve services and outcomes and stay abreast of issues created in part by a dizzying rate of change in the rehabilitation community.

In 1984, the Alabama Division of Rehabilitation Services started a journey of organizational change which has continued unabated (Stephens, 1988). One of the first efforts conducted after the agency allowed total staff to participate in strategic planning was a thorough review and revision of both policy and service delivery processes. By today's standards, it would be considered streamlining at its best. An ongoing concern for the Alabama agency has been unlocking the secret to stimulating a continuous effort to examine existing processes and make necessary revisions, regardless of the current perception of the goodness of the process in question.

Most current initiatives in state governments contain some elements of streamlining, whether called by that name or not.

Since the early 1990's, the Texas Rehabilitation Commission (TRC), generally considered to be an outstanding state rehabilitation agency, has worked to streamline its processes and bring a streamlining philosophy to its operations, including the measurement of quality in the rehabilitation process (Schwab, DiNitto, Simmons, & Smith, 1996). The TRC effort has been described as reengineering, and consequently contains many of the elements considered essential to effective streamlining. Needless to say, the TRC effort is much broader and more comprehensive than efforts typically referred to as streamlining.

The Michigan Rehabilitation Services (MRS) has also enjoyed a stellar reputation for high quality rehabilitation work and has been touted as having one of the best human resource development programs in the nation. Beginning in the late 1980's and continuing to the present, MRS has placed great emphasis on "performance excellence," a series of strategies developed to enhance service quality and change the basic culture of the Michigan rehabilitation agency from that of a more traditional state agency to a state-of-the-art organization (Estell, 1994). Many of the strategies used by MRS involve principles common to streamlining.

Streamlining as an activity, a process, or a philosophy has been widely used within the state-federal program of rehabilitation, primarily by state rehabilitation agencies. As can be seen from the above examples, much of this activity has been ongoing for the past two decades. What circumstances have conspired more recently to compel stakeholders in the larger rehabilitation system to formalize streamlining as a primary process for creating change?

Current Trends

Both federal and state governments are heavily invested in attempts to stem the tide of so-called out-of-control bureaucracy in the late 20th century. The Paperwork Reduction Act, downsizing and streamlining mandates, and executive branch attention to making government "leaner and meaner" reflect current federal initiatives intended to reduce the size of government and at the same time make it more efficient and effective.

In state government settings, there currently exists a plethora of initiatives, many touted as the answer to bureaucratic ills. Included among those initiatives are the following:

- privatization of government services,
- total quality management (TQM) programs,
- resource redirection, including the reduction of resources after redirection, and

- continuous improvement programs.

Most current initiatives in state governments contain some elements of streamlining, whether called by that name or not. Most require some identification of desired outcomes, an analysis of efforts required to achieve those outcomes, and some comparison of desired future operations to current operations.

Streamlining Defined

Streamlining can be simply defined as an "attempt to make organizational processes more efficient," especially through cutting or reducing unnecessary steps in a process or in a set of work activities (Stephens, 1996). Streamlining is but one tool in a larger tool kit commonly known as reengineering, popularized in the more recent management literature (Hammer & Champy, 1993).

Streamlining activities, *per se*, do not require decisionmakers to question the overall effectiveness of a process, although most streamlining activities lead naturally to questions regarding whether or not processes are producing desired or needed outcomes. In the state-federal program of rehabilitation, the streamlining initiative sprang from the convergence of environmental factors and issues mentioned earlier, the three C's. In 1993, leaders of the state-federal program met at the Aspen Institute to discuss the need for streamlining the program and entered into an historic agreement which has resulted in streamlining activities being conducted in most of the state rehabilitation agencies in the country (RSA/CSAVR, 1996).

It is important to note that there is a philosophical undercurrent to streamlining activities which can be traced back two or more decades and connected to the larger shifts in society and the rehabilitation community mentioned earlier in this article. Those undercurrents include the following precepts:

- Traditional notions of dysfunction in organizations and organizational processes reflected a belief that people become dysfunctional and that dysfunction, in turn, produces dysfunc-



tional processes and systems. Streamlining approaches require the belief that processes and systems themselves can become dysfunctional and in fact are often at the root of many organizational evils.

- A corollary to the idea of organizational dysfunction is that of searching for *deviance* in organizational processes rather than searching for *deviants* among organizational members. A search for deviants usually results in someone being punished rather than an examination and analysis of existing processes and functions.

- Many government organizations have traditionally waited for directional signals from legal authorities, legislating bodies, and the issuance of rules and regulations in order to make significant changes in the way business is conducted. In the current environment, waiting for directional signals is akin to being left in the starting blocks when the race begins. While legal authorities cannot be ignored, neither can consumers of services and other constituents and stakeholders. Organizations must develop faith in their own ability to anticipate needs and trends and act upon them before being told to act.

- Traditional notions of management dictate that management take re-

sponsibility for acting on the need to improve processes and systems. Current practice dictates the understanding that those closest to the process, including those who use the process as a work tool, are perhaps the best equipped to analyze and ultimately restructure those processes. It follows that those closest to the process should be the first to be consulted about changing the process.

Streamlining Issues

The following issues were originally raised in an editorial in the *Journal of Rehabilitation Administration* (Stephens, 1996) and are still relevant to any discussion of streamlining efforts in general and state-federal rehabilitation program efforts in particular.

- Streamlining, while geared toward making processes more efficient, will not necessarily make them more effective. If the process is flawed, no amount of streamlining will cause the process to produce better outcomes. A 1966 Volkswagen produced with streamlined processes is still a 1966 Volkswagen.

- Streamlining of processes may have little or no effect on other important variables which are known to influence outcomes. For example, policy, organizational systems, and supervi-



sory and leadership behaviors have tremendous effects on the quality of outcomes produced in an organization. Lack of attention to these variables may blunt the best of streamlining efforts.

- Streamlining activities can have unintended and unanticipated consequences for organizations. Even relatively small changes in processes can sometimes significantly alter the daily fabric of behaviors and interactions in organizational life. A simple change in what is attended to, what is counted, or what is focused upon can sometimes have profound effects which cannot be predicted.

- Streamlining may simply not go far enough to create major systems changes, which some believe to be necessary for all government programs. Is it enough to make processes more efficient? Should major changes be made which go far beyond process improvement?

In addition, there is now enough streamlining experience in state rehabili-

tation agencies to begin drawing some tentative conclusions about the process of streamlining and what can be expected as a result of the activity. In the southeast, 11 of 12 state rehabilitation agencies have participated in the formal process of a streamlining review and the following observations can be made (Stephens, 1997):

- Streamlining the process used for providing rehabilitation services often results in a search for the rationale for doing things a certain way. There is a tendency in organizations to forget why business is conducted in a particular way. Once analyzed, it is often feasible to alter the process because the rationale is no longer applicable. The ability to constantly ask "why we do it this

way," especially if posed by an outside peer, can be a powerful incentive for deleting unnecessary requirements.

- Streamlining reviews serve as powerful reminders to organizational members that the power to make decisions to do things differently resides largely within the organization. The nebulous reference to *they* becomes the specific reference to the more accountable and responsible *we*.

- It is obvious in most streamlining reviews that much of the clutter in rehabilitation agency processes was placed there for good reasons: the desire to protect the rights of service recipients, the desire to right a perceived wrong committed by an organizational member, or an attempt to capture the intent of new laws and regulations. Unfortunately, often there has been little attempt to root out outdated or misguided clutter before moving on to new requirements.

- No matter how frequently or intensely organizations conduct stream-

lining type activities, inconsistencies and flaws in processes are almost always uncovered in subsequent reviews. Infrequent streamlining probably has limited value, with much more to be gained through a continuous improvement mode of operation.

- There is much to be gained by having persons outside the organization participate in streamlining activities, including rehabilitation professionals from other states, advocates, consumers, advisory council members, and others. The outside perspective, while not always technically sophisticated, is almost always direct and provides the organization with an unvarnished point-of-view that is difficult if not impossible to find inside the organization.

Beyond Streamlining


One of the primary goals of any organizational change effort is to create greater efficiencies in the processes used in producing desired outcomes and at the same time add value to what is produced. One of the limitations in using streamlining as a major technique for improving rehabilitation services is that while greater efficiencies may be realized, often little attention is paid to increasing the value of what is produced. For example, it is possible to serve persons with disabilities more quickly and provide more choice in the process without improving the quality of employment, which is the ultimate measure of value. It is also possible to successfully streamline processes yet continue to produce undesirable or flawed outcomes. Obviously, streamlining is but a piece of a larger approach to bringing about desired change in rehabilitation, especially if significant value is expected to be added to rehabilitation outcomes.

Based on the preceding discussion of streamlining and recent experience in participating in streamlining reviews, the following recommendations are offered which should enhance the capacity of the state-federal vocational rehabilitation program to assist persons with disabilities in achieving more valuable outcomes.

- Before engaging in comprehensive streamlining of all processes, state rehabilitation agencies would be well advised to promote full scale discussion and analysis of the desired outcomes they and their constituents desire, including but not limited to a market analysis, an analysis of mission and long-range vision, and a comprehensive effort geared toward developing the commitment of all organizational members.

- Rehabilitation organizations would do well to borrow another concept from the management and organizational literature, that of reengineering. Reengineering is defined as the "fundamental rethinking and radical redesign of... processes to bring about dramatic improvements in performance" (Hammer & Stanton, 1995). At least one rehabilitation agency, the Texas Rehabilitation Commission, has adopted a reengineering approach to examine key processes. Reengineering requires a more comprehensive approach to adding value to agency outcomes.

- Organizations must consider and subject to analysis other organizational variables which have proven to be associated with productivity and high quality outcomes. These include, but are not limited to, supervisory, managerial, and leadership behavior, policy, procedure and best practice systems, and overall reward systems within the organization. Failure to consider these variables will almost certainly diminish the overall effect of streamlining. Unintended and unanticipated consequences are common outcomes associated with streamlining and other organizational change efforts. Consequence structures have evolved to high levels in all organizations, including state rehabilitation agencies. For every pattern of behavior there is a complex consequence pattern, which, if altered, will often bring about significant changes in individual and group behavior. As processes and systems are analyzed and changed, consequence plans often need to be developed in order to insure predictable outcomes (Daniels, 1994).

The current streamlining initiative in the state-federal program of rehabilitation represents a significant departure and transition from a more traditional era. Old style *command and control* organizations will face significant obstacles in the organization of the future, with flexibility and continuous improvement strategies needed for ultimate adaptability and survival. Streamlining represents a small yet significant step toward a complex future. 

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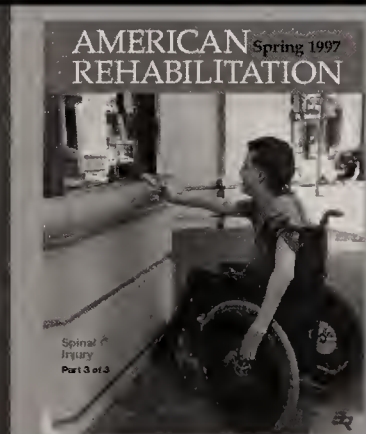
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Recent Issue of American Rehabilitation

Streamlining in Vermont and New Hampshire

This article describes how the state agencies in Vermont and New Hampshire embraced the concept of streamlining to revitalize their organization and reposition their resources for improved services. It examines how the changes introduced in Vermont and New Hampshire contribute a new understanding of choice and consumerism as promoted by the Rehabilitation Act Amendments of 1992 and reviews the process by which Vermont and New Hampshire decided to streamline. The procedures used to accomplish streamlining, staff reactions, and consumer contributions, methods of evaluation, and perceived results will also be discussed.

Maryanne S. Langton

The Rehabilitation Act Amendments of 1992 redirected the focus of the public vocational rehabilitation (VR) program to employment and reestablished the primacy of the relationship between the individual with a disability and the VR counselor. The emphasis on consumer participation and choice, however, promised more fundamental change. The expanded choice requirements called for greater consumer participation in the rehabilitation process and it increased the potential for parity in the relationship between the counselor and consumer.

By updating the public VR program in this way, Congress underscored the need for quantitative and qualitative changes in the 82 VR programs operating in the United States and the trust territories. To prepare for the changes, the Council for State Administrators of Vocational Rehabilitation (CSAVR) and the Rehabilitation Services Administration (RSA) began meeting to restructure and redesign the VR program. While the leadership of CSAVR continued seeking agreement on a methodology to streamline the program, each state administrator began to think about possible approaches to the challenge of increasing quantity and improving quality within existing resources.

In 1993, the state agencies in Vermont and New Hampshire, each adopting a different approach, committed themselves to a streamlining process in order to increase productivity and to improve quality. Vermont and New Hampshire are small rural mountainous states bordered by the Connecticut River; their scenic landscapes attract tourists throughout the summer

and winter months. In many respects, they have a seasonal, service economy. They enjoy a countryside made up of classic New England villages. While Southern New Hampshire and Burlington, Vermont, have attracted a significant urban population, they are thus far atypical. Both states have been successful in meeting their goals. The direction and design of the streamlining efforts reflect the states' individuality. Differences in management styles and philosophies also influence the strategies the organizations have chosen to implement change.

Vermont's Approach

In Vermont, the formal planning process began with a 2-day retreat. All agency managers were invited to participate in the development of a new 5-year plan. The goal was to increase productivity and to improve the quality of the vocational rehabilitation experience for the consumer. The state agency was interested in identifying and eliminating delays in the delivery of services, forming closer relationships with consumers, and removing some pressures from the counselors. The management team hoped to use the planning conference to engage in some creative problem solving. They retained a consultant—a motivational speaker—to set the tone for the conference. He began his presentation as a dialogue, by asking the participants four simple questions; these and the participants' responses follow:

QUESTION ONE: How does the state agency measure success?

ANSWER: We measure success by the number of people employed.

QUESTION TWO: How many people were employed last year?

ANSWER: About 500.

QUESTION THREE: How many people will you employ this year?

ANSWER: About 500.

QUESTION FOUR: How many people do you expect to employ next year?

ANSWER: About 500.

Within the time required to ask and answer four questions, the consultant had convinced the management team of the need to commit to change. The participants developed a new mission to become a consumer directed agency by 1999; and before the 2 days ended, the management team had developed a strategic 5-year plan to realize that mission. They called it Vision 2000.

The complexity of directing a change process that involved a comprehensive needs assessment of all agency customers quickly became self-evident. While the commitment to change had occurred rapidly, the actual implementation was much slower. Consumers, employees, and providers all expressed different needs. The challenge was to sort out the conflicting needs into a single strategic plan. That process encompassed many meetings and resulted in many drafts of the document. A consultant from GC Consulting was hired as a neutral party to provide an objective assessment of organizational progress toward change and to continue the momentum set in motion at the management retreat. The management team had interviewed eight consulting firms before they made their selection. They were pleased with the progress made the first year, during which the Vermont Division of Vocational Rehabilitation also applied for and received a demonstration grant from RSA entitled: "Vermont's Consumer Choice Demonstration Project." By the end of 1994, the management team and GC Consulting had heard from all constituency groups and completed a draft plan. Meanwhile, the consultant prepared all agency staff for the eventuality of change. He concentrated on building communication skills. Staff



David Lamb of the Business Enterprise Program (Randolph-Sheppard Program) is engrossed in streamlining details as Team Leader Steve Wolf briefs the team from Services for the Blind.

learned how to resolve interoffice issues and to feel more comfortable with the organizational change process.

In September 1995, the Vermont Rehabilitation Advisory Council (VRAC) met to outline their recommendations for a more consumer directed organization. It is the purpose of the VRAC, which is made up of a cross-section of consumers, employers, and service providers, to promote the most effective practices in the treatment of consumers, in the design of physical environments and in the provision of services. They identified organizational barriers and brain-stormed solutions to removing them.

The Future Directions Task Force

That same month, the Vermont Division of Vocational Rehabilitation (VDVR) created a task force to build a new strategic plan based on the recommendations of the VRAC. The Future Directions Task Force, consisting of 20 individuals, consumers and staff members, met for a 3-day retreat and developed a draft 3-year strategic plan. At the recommendation of the VRAC, the

Future Directions Task Force forwarded the draft plan to the Policies and Procedures Subcommittee, which is made up of consumers and the Client Assistance Program director. This subcommittee was charged with the responsibility of making final recommendations to the full VRAC. VDVR also shared the plan with the Vermont Coalition for Disability Rights (VCDU), an organization made up of 30 statewide consumer groups who also provided grassroots support of the plan throughout the implementation process. Two months later, the VDVR Administrator, Diane Dalmasse, held two statewide meetings to talk about the VDVR Strategic Plan. Invitations were extended to all staff to review Vision 2000 and share their thoughts with the Future Directions Task Force and the Vermont Rehabilitation Advisory Council. Through a series of simulations, staff were en-

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couraged to try different service delivery approaches. Some were consumer friendly; others were not. As a result of these experiences, staff in different locations initiated independent projects to make their offices more welcoming to visitors. Not everyone at the meetings was receptive to the new direction the agency had embraced, but most could see the benefits of working more closely with the consumers. At the end of November, the Future Directions Task Force combined the recommendations of all DVR staff, the Policy and Procedures Subcommittee, and the VRAC into a final version of Vision 2000. By the middle of December, the Vermont Rehabilitation Advisory Council approved Vision 2000.

The state administrator instituted quarterly meetings with all staff using interactive video. At these meetings, they would discuss the progress and problems in implementing Vision 2000. Additional feedback and followup on Vision 2000 occurred early in 1996 through four regional consumer focus groups held to review and react to the VDVR Strategic Plan. A series of regional meetings were held among regional office staff for the same purpose.

Within 1 year of the first 2-day retreat initiating the streamlining process, Vermont had articulated a vision for the future, had designed strategic goals, embarked on a process of regular monitoring of agency progress, retained a professional systems change consultant, developed plans for new configurations for a streamlined agency structure, and began experimenting with new strategies to expand consumer choice.

Some staff believe that many of these changes would not have been feasible to even contemplate were it not for recent advances in technology. The personal computer, connections to the Internet, voice mail, and fax machines provided the flexibility to convert secretarial positions to human service aides. The interactive video made it possible for staff in all locations to meet regularly with the management team. In other instances, innovations in one area seemed to trigger changes in another. Counselors turned their attention to consumers and services based on choice; supervisors turned their attention to working in the field with the counselors and consumers.

It is clear that the major force for change within the service delivery sys-

tem was the choice project. The management team regarded the choice project as a laboratory for new service strategies. The director of the choice project and four counselors revamped the role of the VR counselor. Once the primary decisionmaker, the counselor stepped back to promote decision-making as a consumer/educator. The counselor would facilitate the decisionmaking process by presenting the full range of choices available, assess the contributions that each good or service might make to the VR process, and provide timely opinion as choices were made. By turning the process on its head, the choice team can exact more consumer interest and participation. At the same time, it remains interesting to the counselors, because they learned how to best prepare each individual to make the best available choices. Every interaction presented an opportunity to learn more about the consumer and his experience and readiness for choice. Learning to assess accurately those areas where consumers required no assistance and identifying areas where individuals needed more information and support became crucial for success. In Vermont, they now believe that counselors need more skills, not less, to effectively function as a counselor/educator. Counselors do not want consumers to fail. They do however want them to have the joy of making their own choices. State Administrator Diane Dalmasse expresses the philosophy of the choice project this way: "We don't want to be doing anything for anybody that they could be doing for themselves."

As new strategies for choice demonstrate success, the agency tries to introduce them into the Title I VR Program. Rather than expanding the choice project, the agency selects strategies that have proven effective. The agency is careful to educate all staff. People who never come face to face with a consumer are routinely informed of innovations. In this way, support staff understand the importance of their role in the change process and they can identify what needs to be done to implement changes. Since demonstration projects



Interpreters translate "vision" as New Hampshire staff meet at agency retreat to begin the process of change.

are not bound by the usual financial and program regulations that apply to the Title I program, each counselor in the choice program has a checkbook to purchase goods and services for consumers, as needed, throughout the rehabilitation process. The ability to write a check for a necessary good or service eliminates any delay that might occur in a state system of purchasing. Checkbooks have speeded up the process and made it possible, in some instances, to provide the services the same day that the Individualized Written Rehabilitation Program (IWRP) is developed.

Some staff say that the most difficult aspect of streamlining is introducing the proposed changes into the government system. When the state agency sought to implement the checkbook strategy into the Title I program, they had mixed results but were pleasantly surprised by the enthusiasm of the business unit to market this idea to their state counterparts. On the other hand, the agency learned that not every counselor is skilled in balancing a checkbook. Now, each district office has a checkbook, but not necessarily each counselor.

In some field offices, consumers who return to the agency after many years express some confusion at all the changes and the pace of progress. As a result, the administration stresses that each person should be encouraged to go at his/her own pace. Just because there is the capability to decide, develop a plan, and make a purchase the same day doesn't mean that it will work for everyone. Staff, on the other hand, are quite invested and excited about their new agency. One person said that it was the most exciting thing that he has seen in 25 years.

Initially there was concern that some more senior staff might not adjust to the changes. In actuality, senior staff are frequently in the forefront making the changes. Richard Hutchins, a regional manager in Burlington, reflecting on the streamlining initiative, stresses that the process has not been a linear one with discrete identifiable steps. He describes it as a process of evolution in which changes occur concurrently. In

his mind, the success of the streamlining process is due to the original goal of increasing consumer direction of the agency and injecting more ideas into the process. He views the choice project, the initiation of consumer satisfaction surveys, and focus groups as mechanisms to increase feedback. He feels the opinion is very helpful to assess agency performance, to know what the agency is doing right, and to identify areas in which the agency could improve.

When Vermont VR personnel initiated their streamlining initiative, they framed some general objectives.

Throughout this change process, the management team has successfully communicated its interest in hearing and implementing new ideas. The state agency has contacted other states for as much information on streamlining as possible and agency personnel have visited other states to exchange ideas. Staff say that the volume of consumer input coupled with the influx of new ideas has enabled them to look at the entire VR process and that they feel comfortable asking questions about every aspect of it. For example, they question why it should take 60 days to determine eligibility and why should one counselor meet with one consumer when one counselor, or several counselors, can meet with several consumers. In another location, counselors and consumers have designed a one-page IWRP that they describe as more user friendly. Jim Alexander, regional manager in Wa-

terbury, believes that the agency would not have come as far without the structure that was set up in 1993.

When Vermont VR personnel initiated their streamlining initiative, they framed some general objectives. They hoped to serve more people effectively, increase productivity, and increase the quality of the relationship with their consumers. They have evaluated the choice project every 6 months, evaluated agency progress on established goals every 3 months, and instituted consumer satisfaction surveys on a regular basis. When they started the planning process in 1993, they had achieved 546 rehabilitations. That changed to 581 rehabilitations in the second year and 664 in the third year. In FY 1996, they rehabilitated 683 people. Of particular interest is that the state agency reports that they have doubled the annual earnings of rehabilitated consumers. In 1995, they conducted a 5-year survey on duration of employment, and they found that 78 percent of consumers remained on the job 5 years after placement. The state agency takes great pride in the degree to which the process to date has been consumer directed, and Diane Dalmasse is equally pleased with the way staff have seized the initiative for streamlining the process and given it their full support.

This year, the agency is working with a new 360 degree evaluation process in which each employee is evaluated by his/her supervisor and the consumers, providers, and peers with which the individual works. Vermont staff have not finished with their streamlining initiative. They will continue to experiment with new ways of opening up the new process. Enthusiasm is high, and the 40 percent increase in rehabilitations since 1992 is certainly noteworthy.

New Hampshire

In 1993, the director of the VR agency in New Hampshire retired after a 30-year career with the agency. Paul Leather, a senior administrator in vocational rehabilitation became the director. The Department of Education underwent a reorganization and its staff

began looking for strategies of becoming more consumer responsive. In January 1993, the changes pursuant to the Rehabilitation Act, as amended, became operational. These three external events culminated in New Hampshire's decision to streamline the agency.

New Hampshire staff developed three goals. They wanted to promote faster and more efficient services, produce more employment outcomes with the same resources, and place more focus on the customer.

The statewide meeting allowed every person to hear for him/herself that the leadership team valued everyone's participation.

During the first year, a consultant was hired to work with the newly established 10-member leadership team. The consultant helped the agency develop a mission, a vision, organizational values, and standards of performance; and he continued working with the agency as the streamlining process was carried out. The agency eliminated the role of the regional supervisor. Regional supervisors became regional leaders, with whom counselors could consult for help in responding expeditiously to a consumer when confronted with obstacles. The regional leader assumed a combination trouble shooter, service support, and personnel generalist function. In the spring of 1994, Paul Leather requested technical assistance from RSA Regional Commissioner John Szufnarowski on New Hampshire's plans for reorganization. The technical assistance was provided

and additional technical assistance on the development of a streamlined policy manual was requested and granted. In the fall of 1994, the agency invited the University of Georgia Human Resources Institute to offer consultation on developing standards of performance and baselines for the standards. Consultation was also provided to the leadership team on policy development, a case review process, and consensus building. In 2 years, New Hampshire had reorganized from a traditional organizational hierarchy to a flatter team structure; had developed a vision, mission statement, and values; revised their policy manual to 30 pages; and developed standards of performance. The state also had begun a multiyear training and consultation effort to phase in self-directed teams in each regional office across the state. Agency staff were hard at work developing a case review guide and learning the dynamics of consensus. Throughout this process, New Hampshire used training and consultation. Each member of the leadership team attended the executive leadership program at the University of Oklahoma. As each team member cycled through the program, that person would select a specific agency project for him/herself. In this way, each member of the leadership team contributed to the viability of the team effort while simultaneously developing personal skills and exploring individual capabilities. Gradually, the program was made available locally through Assumption College. Two classes have now participated in the New England Leadership Series. The proximity has opened up the program to every person in the agency.

In January of 1996, the vice chair of the Rehabilitation Advisory Council advocated for the development of benchmarks in quality standards. Standards were also developed with the community rehabilitation providers through the leadership of the Rehabilitation Advisory Council. In May 1996, a Regional Conference on Streamlining was held at Assumption College. New Hampshire sent seven representatives to the conference. During the

conference, the delegates from New Hampshire really enjoyed hearing what other New England states were doing to streamline. They had an opportunity to meet as a group and decided to hold a statewide meeting in June to synthesize the new learning that had occurred in the leadership team into a shared learning experience for the rest of the agency. Interested in an informal setting, the leadership team selected a camp as the site for this meeting. For 3 days in June, state agency staff assembled at a remote campground near Wolfeboro, New Hampshire. Through a series of workshops, discussion forums, and outdoor team-building exercises, the leadership team members, regional leaders, and counselors brain stormed, debated, and created new plans for their regional offices and new roles for themselves.

The location and the timing of the event provided a needed opportunity for the entire staff to view the progress and plans of the agency as a single team. For 3 years, the agency leadership team had trained, consulted, and implemented a series of continuous changes in the organization. Staff communicated with one another in a formal way through various committees, but as the committee assignments changed, the staff members changed and the message communicated could change with the messenger. As a result, some field staff were experiencing confusion or ambivalence about the changes. They did not always hear a consistent message or always feel confident that they were an integral part of the change. The statewide meeting allowed every person to hear for him/herself that the leadership team valued everyone's participation. As informal organizational communication and learning occurred, the values and expectations for authentic participation became more clear. As the field staff gained confidence in the process, they participated more actively and contributed a series of original ideas and solutions. The participants maximized the experience. They seemed to emerge from the deliberations more closely linked to the streamlining process, their customers, and

each other. This meeting initiated the 1997 financial and program planning process for the agency.

Each regional team returned to the office to develop new plans for customer-friendly services. The teams developed individual team proposals, suggested budgets, and listed any other equipments or supports that they would need to accomplish their goals. They then met with the leadership team to negotiate budgets and commit to outcomes for the year.


New Hampshire rehabilitated 1,150 people in 1993, 1,217 in 1994, 1,275 in 1995, and 1,401 in 1996; this represents an increase of 27 percent in the number of rehabilitations since 1992.

The number of severely disabled individuals placed has increased by 40 percent. Three other state agencies in New England have come to New Hampshire to learn about its streamlining process. New Hampshire does

not feel that it has finished with its process. The 1997 fiscal year was the first year that all locations initiated their own program plans as part of the agency budget and planning process. New Hampshire has had the fastest growing economy in New England and, because it does not have an income tax, many employers find it a desirable location for business. The employment outlook for the state is promising and the potential of the VR agency to increase rehabilitations looks equally good.

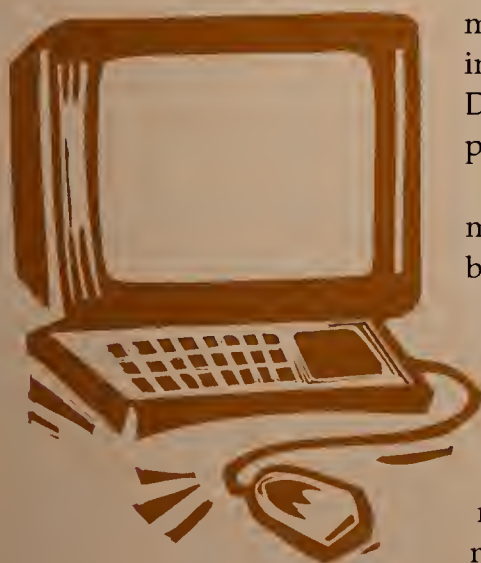
Vermont and New Hampshire have contributed to the region's understanding of the possibilities of streamlining. Shortly after the regional conference in May 1996, New England CSAVR charged a continuous improvement workgroup with the task of developing a regional plan and regional benchmarks for streamlining. Because of the experiences each has

had over the last 3 years, both states were able to provide strong leadership in this group. Vermont's most visible successes have developed from its choice project and its employment program with industry. It has developed a possible prototype for the public rehabilitation agency of the future. New Hampshire has modeled the concept of teaming and continuous improvement, suggesting new possibilities for providing customer friendly services through regional self-directed work teams.

The VR agencies in New England have benefited from the streamlining initiatives underway in Vermont and New Hampshire. These two states have melded traditional program values with newer values . . . they have strengthened their programs and helped us envision new organizations becoming the future of the public VR program. 

President's Committee on Employment of People with Disabilities Now on the Internet

The President's Committee on Employment of People with Disabilities is now accessible on the Internet via the World Wide Web.



Using the committee's website address—<http://www.pcepd.gov>—visitors may tap into information on a variety of disability employment issues, including fact sheets on statistical data, job accommodations, the Americans with Disabilities Act, recruitment, interviewing, hiring, and communicating with people with disabilities.

Additional resources available online include a list of the President's Committee's current projects and staff contacts; press releases; publications; speeches by Chairman Tony Coelho, President Clinton, and others; conference information; and a directory of state commissions, committees, and councils.

The President's Committee on Employment of People with Disabilities is a small federal agency based in Washington, DC. The committee's mission is to facilitate the communication, coordination, and promotion of public and private efforts to enhance the employment of people with disabilities. The committee provides information, training, and technical assistance to America's business leaders, organized labor, rehabilitation and service providers, advocacy organizations, families, and individuals with disabilities. It also operates the Job Accommodation Network (JAN), a toll free information service on the Americans with Disabilities Act and employment accommodations.



Organizational Transformation: A Bold Journey, Not a Guided Tour

Lynnae M. Rutledge

For many years, the profile of the public vocational rehabilitation (VR) program has been that of an unassuming, almost invisible, service delivery system. We have seen greater value in promoting the consumers' achievements than our role in their success. Our resources have been key to the development of a multimillion dollar industry of vocational rehabilitation service providers. Yet, that very industry seems to be nipping at our heels as changes are contemplated in the Reauthorization of the Rehabilitation Act. Often, in the eyes of the public, the successful employment of the disabled person that we have assisted is not

linked to the public vocational rehabilitation program; instead, the success is linked to the private sector provider or other partner who made the direct link with the employer.

The current climate presents real and perceived threats. The public is skeptical about the need for government, and there are concerns about our outcomes. The very value of the public vocational rehabilitation is being called into question.

To meet this challenge, the Oregon Vocational Rehabilitation Division (OVRD) has embarked on a change initiative that will launch us into the 21st century. Our mission provides the necessary foundation for our efforts: to assist Oregonians with dis-

abilities to achieve and maintain employment and independence. To better achieve that mission, we have embraced the need for significant change in the way we do business. Given the threats at hand, we recognize that our survival is at stake.

Organizational transformation is our goal. We are transforming the way we do business through a commitment to providing world class customer service, enhancing our utilization of technology, redefining our relationships with employers and other critical partners, creating more flexible personnel approaches, and evaluating our performance. We are challenging the system and ourselves to better demonstrate our value and worth.

We see organizational transformation as a bold journey. This article shares our experiences thus far and the lessons we have learned along the way.

Recognizing the Need for Change

Organizations that attempt this journey must grapple with a variety of issues. Clearly, leadership for any change strategy must be demonstrated by active commitment from the very top of the organization, and that commitment must spread throughout the organization. Organizational transformation represents a shift that calls for new ways of thinking: about staff roles, about resources, about service delivery, about every aspect of doing business.

OVRD's approach has been in building a strong foundation and weaving leadership skill development throughout the fabric of the organization and in taking advantage of multiple opportunities to develop the leadership skills of OVRD staff.

In the late 1980's, the University of Oklahoma launched an innovative Executive Leadership Program to enhance the leadership skills within the public VR program. Since the program's inception, our administrator, members of the OVRD executive staff, and key members of the management staff have successfully completed the 4-week course. The program has helped OVRD focus on and develop practices associated with exemplary leaders. These practices include the following.

Challenging the Process. We have searched for and found challenging opportunities to change, innovate, and improve our system and processes. We are promoting experimentation and the art of taking risks; and we are learning from our mistakes.

Inspiring a Shared Vision. In conjunction with the creation of a comprehensive business plan, OVRD executive staff has renewed the agency's mission statement and communicated an uplifting organizational vision and statement of shared values.

Enabling Others to Act. We are fostering collaboration by promoting the mis-

sion, vision, and values with our staff and other partners. We actively promote the expectation that staff make decisions locally and rely on their discretion in prudent decisionmaking and professional judgment.

Modeling the Way. We look for ways to set the example. Many of our people have been involved in leadership training and activities. This has helped to create an array of positive role models throughout the organization.

Encouraging the Heart. Recognition of individual and group contributions is being incorporated into our agency culture. A peer recognition program is a highlight of our statewide all-staff in-service session.

As an adjunct to the executive leadership development activities, OVRD staff have participated in the University of Oregon's Pacific Program, the University of Washington's Emerging Leaders Program, the State of Oregon's Leadership Oregon Program, and the Department of Human Resources Human Services Academy. Since 1990, more than 50 of our employees have participated in leadership training courses and related activities. This represents a significant human investment in change.

Like many other state VR agencies, we are seeing a shift in the profile of our workforce. Many of our long-term service delivery personnel are moving into retirement. Recruitment and selection of new staff has infused new blood and new life into local offices. We continue to have a consistently high percentage (December 1996: 17.9 percent) of people with disabilities in our workforce (65 of 362 employees). We are actively seeking to increase our diversity by hiring and promoting more people from minority cultures.

Like other state VR agencies, OVRD was bitten by the streamlining bug. We recognize now that streamlining is best viewed as a first step in the longer term journey of organizational transformation.

Here in Region X, the streamlining initiative was dynamically led by Keith Anderson, then administrator of the Alaska combined agency. With the tech-

nical assistance and support of the regional office, each state's rehabilitation services system was analyzed. Through self- and team assessment, we began to see that much of the excessive paperwork and duplication of effort was of our own making. It had become common to blame the requirements in the federal legislation for our unwieldy process. We soon found that *we* had created many of the obstacles and *we* could remove them.

Before proceeding with the Oregon streamlining process, we initiated communication with other state VR agencies, including Georgia, Wisconsin, New York, Texas, Maine, Idaho, and Washington. Similar to other states' approaches, OVRD started by assembling teams of staff, consumers, and other partners to look at the current steps in the rehabilitation process. An extensive series of recommendations were drafted and many implemented. A significant reduction in paperwork resulted, but minimal impact was realized directly on employment outcomes.

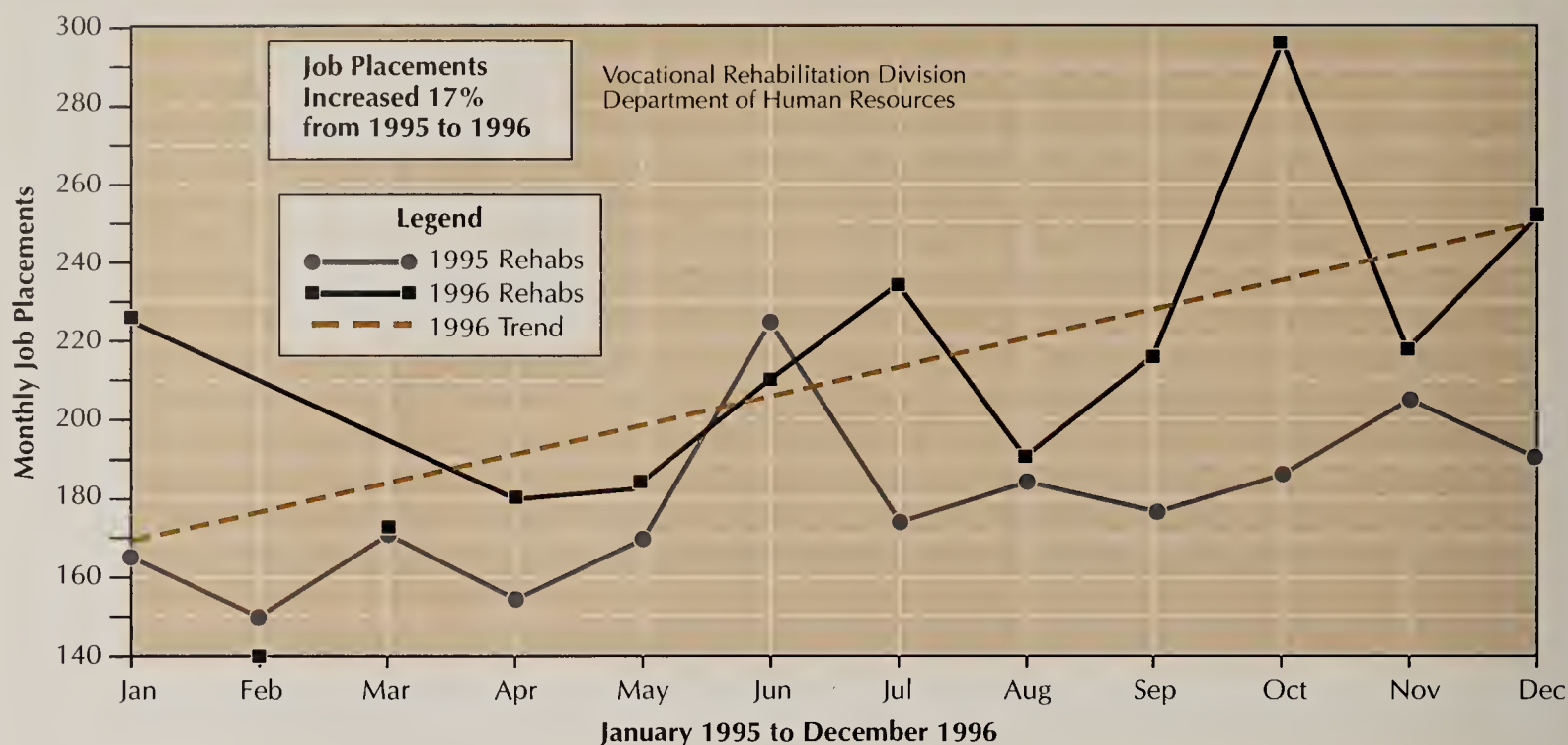
As OVRD pondered its next steps, all roads appeared to lead to automation of our case management system and a better utilization of technology. Additionally, we recognized that in order to achieve greater productivity and increase our success with employment outcomes we needed to change, not merely tweak, the existing system.

Development of the OVRD Business Plan

As is common with most state VR agencies, OVRD has historically used a variety of tools for planning. We have an approved 3-year state plan with annual updates. As required in the 1992 Rehabilitation Act Amendments, we have a strategic plan. We have a state plan for independent living. We have developed biennial goals and objec-

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Chart 1. State of Oregon Rehabilitation Services Rehabs



tives. Given the dynamics of possible consolidation of workforce programs and the discussions associated with reauthorization of the Rehabilitation Act, we saw an advantage in pulling these efforts together into one, coherent plan that would blend strategies, reflect our agency mission, vision, and values, and guide us into the future.

The OVRD business plan, introduced at the statewide all-staff inservice session and distributed electronically as well as in hard copy in 1996, is a tool that will help shape the way we perform our work and communicate with all those affected by our services.

The business plan activities are supported by fiscal resource management, personnel services, staff development, and a system of performance measurements. It includes detailed action plans, deliverables, and timelines that reach from 1996 to the year 2000. The OVRD Executive Leadership Team meets quarterly specifically to review our progress, negotiate midcourse corrections, and celebrate accomplishments.

While planning documents are good indicators of an organization's intentions, deliverables are essential. For this first year (1996-97), the major deliver-

ables have been identified for each of the business plan components. The deliverables range from communication of the vision to providing customer service training for all staff to implementation of the automated case management system.

The business plan is a dynamic and evolving management tool that will be continuously evaluated and reviewed. Branch level business plans are being developed and revised to provide the "how to" and "hands on" component for our efforts to transform the organization.

World Class Customer Service

Building on our initial introduction to "world class customer service" in the University of Oklahoma's Executive Leadership Program, OVRD has embraced the concept of *customer delight* and designated improved customer service as a cornerstone in our transformation.

By the end of 1996, all OVRD staff, including Rehabilitation Services staff, central office administrative staff, and Disability Determination Services (DDS) staff, had attended inhouse train-

ing on world class customer service. We believed it was important for all staff to be introduced to the same concepts, to learn the same vocabulary, and to share in the same expectations. The concepts of cycles of service, moments of truth, and realigning systems of reward, compensation, and recognition have become imbedded in our emerging culture.

On a monthly basis, in conjunction with the distribution of the OVRD newsletter, we highlight examples of internal activities associated with world class customer service. One example is that field offices have significantly reduced the time from initial contact to first appointment with a counselor by scheduling walk-in contact time and appointments within 1 week at the customer's discretion.

In both DDS and Rehabilitation Services, staff at the local level are involved in redesigning the way they deliver services in order to provide more opportunities for customer delight. Striving to achieve excellence as a high performance work organization, such activity leads to greater local level decisionmaking in a participatory work environment.

In recognition of our activities, the State Management Association presented the 1996 Customer Service Award to OVRD. In an effort to pass this honor along to all involved, OVRD has developed recognition plaques to be displayed in each field office and work unit throughout the organization.

In OVRD, we are implementing computer systems for each of the two major program components based on their unique needs. In Rehabilitation Services, we are capitalizing on the development work done by the Washington general agency. We have acquired the Washington case management automated system known as STARS. Recognizing that system acceptance can be enhanced when people are involved in its design and selection of a catchy name, we created a statewide contest to "name the system." The winning entries recommended ORCA (Oregon Rehabilitation Case Automation), which has been accepted as the title of our case management automation project in Rehabilitation Services.

As OVRD underwent an indepth self-assessment through its streamlining efforts, the problems associated with excessive paperwork, duplication of effort, and documentation errors presented a significant management challenge. Automated case documentation, utilizing a system such as ORCA, became the recognized solution.

Given the complexity of developing, implementing, and maintaining an automated case management system that interfaces with our fiscal system, OVRD is choosing to implement ORCA in phases. During the initial phase, which was completed in July 1997, we installed the Washington STARS system with minimal customization.

With our focus on customer service (both for internal and external customers), we continue to focus on meeting the needs of staff. Our existing management reports system is untimely and cumbersome and will be substantially revised with ORCA. To address our immediate needs, a budget staff person designed a system of online "Flash Figures." Staff can now use a tool that visually depicts monthly ac-

tuals, 12-month rolling averages, and the trend line for production (caseload, plans, rehabilitations). This same process of displaying data is being developed throughout the Oregon Department of Human Resources to depict outcomes from services delivered. Indeed, our transformation is netting results on a much broader scale than originally envisioned.

Doing business differently is not an easy process, and achieving change in a bureaucracy is a daunting task.

Transforming the Service Delivery Process

Doing business differently is not an easy process, and achieving change in a bureaucracy is a daunting task. There are inherent limitations associated with the existing system and the status quo. Some of the limitations are linked to agency culture, while others are the result of legislative constraints.

An organizational development work group provided an early focus on changing the way we do business. The work group crafted a set of vision statements, principles, and recommendations. These provided the framework for the development of a Demonstration Project in Rehabilitation Services. The Demonstration Project became the vehicle through which OVRD has reconfigured its rehabilitation services management structure into districts, supported the development of a variety of teamwork approaches, and created advisory committees at the district and branch levels.

The stated goal of the Demonstration Project is to develop and implement strategies for increasing employment outcomes and personal independence for people with disabilities

through community partnerships. One of the deliverables is to demonstrate the use of technology to improve organizational effectiveness. The role of the advisory committees is to review project plans, assess customer delight, and evaluate the effectiveness of the district's service delivery.

The launching of the Demonstration Project was aided by the decentralization of staff resources from the central office Quality Assurance/Program Management staff. Additionally, the transformation efforts have been augmented by learning from the early work done with teams in the Portland area. Benefiting from grant funded assistance from the University of Oregon, staff received indepth training on continuous improvement, building and maintaining teams, and support for change. Early indicators reveal that there have been only limited improvements attributable to teams that can be correlated to staff productivity gains, increased employment outcomes, or enhanced customer satisfaction.

Given the reality of the state civil service system and union contracts, there is a perception that not much can be done to positively reinforce our commitment to world class customer service. We have ample negative reinforcement from the press and the public at large with their perceptions of state workers. However, a commitment to organizational transformation is also a commitment to changing our focus from what we cannot do to what we can do.

Here are examples of practical actions we can take to reward, compensate, and recognize staff as they delight our customers:

- Regularly assess customer satisfaction.
- Assess workplace morale and measure staff satisfaction.
- Act on staff and customer recommendations.
- Recognize staff contributions with celebrations at the state and local levels.
- Seek alternative resources, such as a state productivity fund, for rewarding or compensating staff.
- Explore the limits of the state compensation system to "pay for perfor-

mance" for both management and represented staff.

- Display articles, thank you notes, and photographs of staff and delighted customers in field offices, in agency publications, professional journals, and local newspapers.

- Include the expectations related to customer service in the employee's position description, training plan, and annual performance appraisal.

As Rehabilitation Services implements the automated case management system and redesigns its business practices, there will continue to be changes in the roles of staff. Many clerical staff are moving into casework support roles. Counselors are learning to use their computers and inputting more of their own case documentation. Counselor-clerical staff teams are developing. First line supervisors are shifting their focus to mentoring and coaching.

All these changes require much greater flexibility from all. At the same time, there is a continuing need to assure that accountability is intrinsically linked to responsibility, wherever that responsibility may reside. Staff need to be provided with adequate opportunities for open discussions, peer support, and training in order to be successful in navigating the change process.

Within OVRD, we believe that our success in the future is linked to having a diverse work force and managing it well. We seek to attract, challenge, and reward our staff and develop them for the future. We recognize the value, in fact, the necessity, of building a team of diverse professionals to help us meet the challenges ahead. Diversity in our work force will be the competitive advantage that we put to work every day on behalf of the Oregonians with disabilities that we serve.

One of our core vision statements incorporates our focus: our staff, consumers, and providers must reflect the diversity of the community we serve. We have considerable work ahead to accomplish this aspect of our vision. As a beginning step, we have developed a Cultural Diversity Strategic Action Plan. In conjunction with the State Rehabilitation Advisory Council,

OVRD conducted an agencywide diversity self-assessment. The results of this assessment will help to define the agency's practices and the training needed and assist in developing culturally sensitive, responsive services and other essential activities.

Seeing Employers as Our Customer

Given that our services are designed to yield valued employment outcomes for people with disabilities, we have focused our attention on the needs of the employer as our customer. We are pleased that job placements have increased 17 percent (from 2,145 to 2,509) during 1995-96.

In 1995, Oregon was selected by the President's Committee on Employment of People with Disabilities to develop a business-to-business leadership network. Asserting a lead role, OVRD has worked together with the Oregon Commission for the Blind and the Oregon Disabilities Commission to establish business networks in the Portland and Eugene areas. With a core group of committed business representatives in each of these communities, the Business Leadership Network is increasing the participation of people with disabilities in the workplace and in the marketplace.


Oregon's vision is "to have the best educated and prepared workforce in the nation by the year 2000, and a workforce equal to any in the world by 2010." OVRD acknowledged early on that developing and sharing our accountability measures and outcomes was potentially risky but necessary. Our current key measures include: customer surveys (consumers, employers, and staff), average wage at closure, job retention rate, and cost per successful closure. Results reported for January-March 1997 indicate a client satisfaction rate of 81.1 percent; employer satisfaction, 77 percent; staff satisfaction, 79.5 percent; average wage at closure, \$7.69 per hour (this is 79 percent of the average job order registered with the Employment Department); and 66 percent of our successfully closed clients are employed 18 months following clo-

sure. Cost per closure is a revised measure for 1997-99 and we have not set targets or reported results thus far.

Summary of Challenges: Lessons Learned

Organizational transformation demands three basic commitments of us. First, we must be committed to our customers (staff, clients, employers) and obsessed with providing services of such quality that we delight them. Second, we must blend statistical data with the logic of planning and continuous improvement. Finally, we must be committed to teamwork and partnership. These basic commitments, when woven together, create the fabric of our organization. We are challenged by the simplicity and the complexity of these commitments. We recognize that the survival of the public vocational rehabilitation program may well depend on our ability to be more flexible and responsive to the needs of our customers.

A "can do" attitude goes a long way towards encouraging risks and the results are worthy of celebration.

This is truly a remarkable journey. 



Audio Cassettes of American Rehabilitation

Taped Copies of *American Rehabilitation* are available to blind and physically handicapped persons through local regional offices under the National Library Service for the Blind and Physically Handicapped. Contact your public library for the location of the regional library which serves your state.





Anniversary of the Institute on Rehabilitation Issues

Charles Sadler, CRC

The 50th Anniversary forum of the Institute on Rehabilitation Issues (IRI) was held at the Washington Marriott Metro Center in Washington, DC, on June 1–3, 1997, with approximately 150 people from across the country and overseas attending, including vocational rehabilitation (VR) professionals, advocates, persons with disabilities, educators, and employers.

Fredric K. Schroeder, Commissioner of the Rehabilitation Services Administration (RSA) and Ms. Jeanne Munro, current Director of the Washington Division of Rehabilitation Services and President of the Council of State Administrators of Vocational Rehabilitation (CSAVR) at the time of the forum, greeted the attendees and emphasized the strong state-federal partnership that characterizes the public VR program and the need for IRI to present cutting edge solutions to the challenges facing people with disabilities in achieving meaningful employment and community integration. After the opening session, the three prime study groups convened to present their draft documents on the following topics: "Improving the Achievement of Employment Outcomes," "Developing Effective Partnerships With Employers as a Service Delivery Mechanism," and "Assuring an Outstanding Public Vocational Rehabilitation Program in the 21st Century—Eliminating Barriers to Effective Service Delivery," a topic which directly impacts the streamlining initiative. (A brief summary of the publications and

information on how to order copies may be found at the end of this article.)

During the evening of the first day of the Institute, the participants attended a reception to celebrate its 50th anniversary. In addition, a luncheon was held to close the IRI forum, at which time the university coordinators, chairpersons, and prime study group members were honored for their efforts in the development of IRI publications. Dr. Ralph Pacinelli, RSA Regional Commissioner, served as master of ceremonies and commended the awardees for devoting a substantial amount of time and energy to the IRI process, in addition to their normal workload, and for contributing to the development of publications widely used in training VR program staff.

During the IRI Planning Committee meeting on June 1, the following topics and university coordinators were selected for study during the upcoming 24th IRI cycle: "Field Service Managers and Supervisors: Strategic Leaders in Achieving Employment Outcomes," Dr. Donald Dew, George Washington University; "Achieving Successful Employment Outcomes with the Use of Technology," Dr. Daniel McAlees, University of Wisconsin-Stout; and "Developing Self-Employment and Small Business Opportunities for Persons with Disabilities," Ms. Jeanne Miller, University of Arkansas.

The 24th IRI prime study groups will begin meeting in fall 1997, so that draft documents may be presented at the annual IRI forum scheduled in Washington, DC, May 3–5, 1998. IRI is a cycle of activities originating in the request for

possible topics for study and ending in the publication of documents useful in training and program development. As part of the "streamlining" agreement between RSA and CSAVR, IRI was highlighted as a project to develop guidance and training materials to sustain and expand activities to improve the effectiveness and efficiency of the VR program.

Revitalizing IRI

During the past few years, RSA and CSAVR determined the need to be more actively involved in IRI and to use this activity as a yearly opportunity to rethink the VR process and to improve program performance. The immediate results of this renewed interest have been twofold. For one, there has been increased support and participation by the staff of the state VR agencies. Second, the topics selected by the RSA Commissioner for the past two IRI cycles have been specifically related to improving the quality of employment outcomes achieved by persons with disabilities served by the public VR program.

In order to familiarize all members of the rehabilitation community with RSA procedures for conducting the IRI, it

Mr. Sadler is a VR Program Specialist with RSA in Washington, DC. In addition to coordinating the IRI, he is responsible for the development of VR program monitoring and technical assistance guidance and is a frequent participant in VR program onsite reviews.

may be useful to review the history of IRI, the support organizations, the organizational structure, and the process from topic selection to dissemination of the IRI publication.

Historical Perspective of IRI

IRI has had a long history of cooperation and affiliation among state VR agencies, RSA, universities, and community rehabilitation programs. This affiliation continues to receive strong support today.

IRI is one of the longest running annual events in the human services field. It began as the *Guidance, Training and Placement Workshops* (GTP) in 1947. The original purpose was to discuss subjects of general interest in state VR agencies and prepare training materials for staff, at all levels, in those agencies.

In 1963, the name was changed to the *Institute on Rehabilitation Services* (IRS). Major support for IRS continued as a partnership between the state VR agencies and RSA and, for the first time, universities participated as prime study group coordinators. Funding problems in the RSA Training Grants Program in 1974 caused the name change. RSA shifted financial support for the new IRI to the RSA administered rehabilitation research program. In 1978, the National Institute on Handicapped Research (NIHR), later to become the National Institute on Disability and Rehabilitation Research (NIDRR), was created by law to administer the research program and IRI funding moved to NIHR, which continued sole support through its Research and Training Centers (RTC) program.

Current Organization and Structure

Changes to IRI over the years have been few, but significant, such as in resources, university coordinators, funding agencies, and procedures. RSA and CSAVR have remained consistent supporters and contributors to IRI as have the universities funded by RSA and NIDRR. The basic purpose and focus of IRI has remained unchanged:

- Identify and discuss current issues of importance to the public vocational rehabilitation program.

- Develop materials which can be used by state VR agencies and others concerned about staff development in rehabilitation.

- Publish and disseminate the materials widely to people who provide rehabilitation services to individuals with disabilities.

Since its inception, state VR agencies have been and remain the principal supporters of IRI. These agencies allow release time for staff members to serve on prime study groups and to attend and participate in the annual meeting. They also make significant use of IRI publications. Although once funded by NIDRR, IRI is now solely funded by RSA through cooperative agreements with the Regional Rehabilitation Continuing Education Programs (RRCEP).

During the early spring of each year, topics for the following year's IRI are solicited from CSAVR, RSA, and other appropriate entities.

The Planning Committee. IRI is guided by a planning committee, which provides direction to the university coordinators who manage the prime study groups and are also responsible for completing the following tasks:

- Publicize IRI and solicit from CSAVR and RSA: topics for study, prime study group members and chairpersons, and participants for the annual meeting.

- Discuss topics and recommend four topics for study. The RSA Commissioner, with input from the CSAVR President, selects three topics and assigns each to a university prime study group coordinator.

- Advise the university prime study group coordinators on the marketing and dissemination of IRI publications.

- Recommend strategies for including IRI publications as part of state VR

agency inservice training and regional continuing education programs.

The planning committee gathers once each year during the annual meeting to conduct the managerial business of IRI.

The IRI Process

Topic Selection. During the early spring of each year, topics for the following year's IRI are solicited from CSAVR, RSA, and other appropriate entities. CSAVR and RSA each submit at least three topics to the planning committee. The planning committee discusses the topics and selects those that are determined to be most relevant for study. The selection criteria used by the committee are:

- The topic is currently one of concern to a large number of state VR agencies.

- It is a topic that can be completed within a year.

- There are recognized experts or a body of literature that will be available to the prime study group.

Selection of Prime Study Group Chairs and Members. CSAVR and RSA nominate to the university coordinators individuals for consideration as prime study group members who meet the following criteria: knowledgeable and recognized experts on the topic being developed; able to formulate written ideas; and willing and able to make a substantial commitment of time and energy to the IRI process. Each prime study group coordinator evaluates the nominations and submits to the RSA/IRI coordinator a recommended panel consisting of 12–15 study group members, the majority of whom are state VR agency representatives. The remaining members will be made up of one RSA representative and other individuals who are recognized authorities on the issue under study and/or represent important consumer perspectives.

The RSA Commissioner and the CSAVR President jointly select the prime study group chairs and members. The chairperson will be a current employee of a state VR agency who has demonstrated leadership qualities and good writing and editorial skills and has served on previous IRI prime study

groups. The members of the prime study groups make a commitment to attend three meetings (travel expenses paid by the university, except for the RSA employees) and to prepare materials between meetings of the group. No honorarium is paid as part of the IRI process. In addition, the prime study group meetings are held in cities that have an RSA regional office to enable the participation of an RSA employee.

Prime Study Group Meetings

The first prime study group meeting is devoted to a discussion of the topic and all of the issues surrounding it from each member's perspective. When the issues have been discussed, they are organized into chapters for the draft publication. These issues are then used to outline potential chapters and to make writing assignments. The members return home to do the actual writing for their assigned portion of the outline.

Approximately 3 months later, the prime study group reconvenes for the second meeting to review the draft documents and to further discuss the topic. At the end of this session, the written materials are reorganized, chapters may be cut and pasted together, and new outlines are developed for missing materials. At the second meeting, chapters may be reassigned to other prime study group members to provide an additional perspective or to further elaborate on specific issues. They will then rewrite that section or chapter, using the first draft as a starting point. This second effort is sent to the prime study group coordinator for duplication and distribution to the members and persons who will attend the annual meeting.

Annual Meeting. Approximately 2 months prior to the annual meeting, the date, meeting site, and issues developed over the previous year are announced to potentially interested individuals. Prospective participants choose one of the topics that will be presented and become part of that topic's expanded study group. Each member is mailed a preliminary report of the prime study group's draft document at least 2 weeks prior to the annual meeting to re-

view, critique, and develop recommendations in preparation for the meeting. At the annual meeting, the prime study group describes the development of the topic, reviews the draft document, and carefully reviews the material for accuracy, comprehensiveness of coverage, reference to state VR agency practices, inclusion of appropriate consumer references and concerns, and other issues. Critical comments, both negative and positive, are recorded for consideration by the editorial committee.

Revision and Report Development. At the completion of the annual meeting, a small editorial committee made up of the prime study group chairperson, two members of the prime study group (one of whom may serve as the following year's chairperson), and the prime study group coordinator, edit the document. The prime study group coordinator subsequently conducts an additional edit of the revised document and sends it to RSA for the first review. During the first review, RSA will informally provide feedback to the prime study group coordinator.

Final Review of Publication Prior to Printing. Upon completion of the final edits, the document is sent to RSA for a final review, which RSA will share with CSAVR. Within 45 days, RSA will provide the university prime study group coordinators with final comments prior to publication.

Dissemination and Impact. Approximately 3,500 copies of each IRI publication, accompanied by an *RSA Information Memorandum (IM)*, are distributed free of charge to RSA central and regional offices, NIDRR, state VR agency directors, State Rehabilitation Advisory Councils, Client Assistance Programs, other RRCEP'S, Rehabilitation Training Centers, Rehabilitation Training Programs, and to the National Rehabilitation Information Center (NARIC). All IRI publications are available in alternative formats. Other copies are sold by the university prime study group coordinators to recover part of the cost of printing and distribution. One year after the date of publication, all remaining copies are sent to the National Clearinghouse on Rehabilitation Training Materials for

further distribution and to maintain a central source for all IRI publications. A marketing strategy is being developed to advertise the availability of IRI publications, to ensure that they are disseminated to a broad range of rehabilitation professionals, and to maintain a single location for obtaining past and future documents.

IRI publications have made a significant impact on program policy and operations and are being used extensively as resource/reference materials and as a means for individual self-development.

The Future of IRI

An important part of RSA's mission is to provide training and technical assistance to state VR agencies on the problems facing rehabilitation service providers and to disseminate and promote the utilization of knowledge resulting from current research. Through IRI, high priority training needs are responded to expeditiously and the study findings on a specific topic are quickly transposed into useful and usable training materials and publications.

IRI publications have made a significant impact on program policy and operations and are being used extensively as resource/reference materials and as a means for individual self-development. State VR agencies and other rehabilitation programs have indicated that IRI publications have contributed content to their training programs that was not available from any other source. The process of developing the IRI publication is a significant event for a member of an IRI prime study group because most of the authors are rehabilitation practitioners who bring a practical perspective to discussions of the topic and the re-

sulting publication. RSA intends to continue its support of IRI to provide VR professionals with an opportunity to develop with their peers the most imaginative solutions possible to improve the work opportunities and the quality of life for persons with disabilities.

Summaries of the 23rd IRI Publications and Ordering Information:

Improving the Achievement of Employment Outcomes. This document is comprised of seven chapters that focus on issues, programs, and models relevant to improving the achievement of employment outcomes for individuals with disabilities. An organizational culture designed to support the attainment of employment outcomes is explored in Chapter One. Chapters Two and Three provide a detailed model for developing the role of vocational rehabilitation in the economic community. Chapter Four offers counselor input into mechanisms and strategies for attaining employment outcomes. Chapter Five addresses the changing world of work. Chapter Six focuses on client education in preparation for employment. Chapter Seven describes various models and experiences from successful self-employment programs.

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Developing Effective Partnerships With Employers as a Service Delivery Mechanism. The second publication focuses on approaches designed to strengthen

the state-federal VR partnership with private sector employers. It addresses the needs of the private sector employer and discusses employers' perspectives, the structure of corporate employment in large and small companies, how employers prefer to be approached, employers' perceptions of the value of vocational rehabilitation, and more. Each section is followed by a list of straightforward ideas on how to improve relations with employers.

Finding qualified candidates is no longer as easy as placing an advertisement in the newspaper. The resounding cry from business across the country is clear: "We need skilled people!" VR is in the position to answer that call. Never before has the opportunity to establish effective relationships with businesses been as promising. The largely untapped pool of potential workers with disabilities represents a valuable resource to employers desperately seeking qualified candidates. The authors believe that the present era of prosperity offers more opportunity than simply increasing the number of "placements" by VR. They recommend how we can further close the gap between business and VR to create a partnership that meets the needs of all the customers involved, including people with disabilities, the companies that employ them, and the vocational rehabilitation staff that represent them.

Chapters include: "Successful Partnerships: The Employer Speaks," "Successful Partnerships: What Do They Mean?" "Successful Partnerships: What Are We Trying To Achieve?" "Successful Partnerships: Are We Speaking the Same Language?" and "Successful Partnerships: Administrators Are You Listening?"

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Assuring an Outstanding Public Vocational Rehabilitation Program in the 21st Century—Eliminating Barriers to Service Delivery. The third IRI document identifies the basic components of a successful VR program, the issues affecting the efficient and effective delivery of services leading to employment outcomes, and strategies for eliminating identified process requirements and other barriers which impede the achievement of successful outcomes.

A system based on core values and principles, the 21st century public VR program exemplifies many characteristics which have been developed in state VR agencies across the country. Examples of effective practices that may be useful to other VR professionals are highlighted throughout this publication, including where to go for further information.

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Redesigning the State Rehabilitation Program in New York State

Lawrence C. Gloeckler

Over the past several years, state vocational rehabilitation (VR) programs throughout the country have been involved in fundamental redesign of the management and delivery of VR services. Recently, the Council of State Administrators of Vocational Rehabilitation (CSAVR) and the Rehabilitation Services Administration (RSA) received the prestigious Hammer Award, given by Vice-President Gore in recognition of their leading the way in the reinvention of government programs. The Vice-President stated that CSAVR "can be proud of your role in the largest reform initiative the United States has seen in this century."

While the following pages detail redesign efforts in New York State, the most important aspect of these efforts, wherever they are undertaken, is the people who benefit from these improvements. Administrative efficiencies, streamlined procedures and "user friendly" approaches mean nothing if they do not provide a better service that leads to a better result for people. People with disabilities, and employers, are the customers of state rehabilitation programs. Any redesign effort must improve our ability to meet their needs. It's that simple. It's that direct.

The Vision

There is an old saying: you won't get to where you want to go if you don't know where it is. That is a gem of wisdom for all of us to keep in mind as we reengineer our services, whatever they may be. It may sound trite, but it is essential to have a clear vision for your improvement efforts. In New York, we

have embraced the vision so eloquently stated in the Rehabilitation Act of 1992.

People with disabilities will . . .

"(A) live independently;

(B) enjoy self-determination;

(C) make choices;

(D) pursue meaningful careers; and

(E) enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society. . . "

We have organized within the New York State Education Department so that all services for people with disabilities, from preschool, through school age, to vocational rehabilitation and independent living services, are administered under the same umbrella, to create a lifelong approach to reach this vision.

Redesigning vocational rehabilitation services will only reach its true potential to the extent that we are successful in the redesign of the rest of the lifelong continuum. However, it is a truly important component and has the potential to be an important catalyst in many more people's lives.

The Context for Redesign in New York

In the late 1980's, New York State's VR program, then called the Office of Vocational Rehabilitation, was mired in controversy and viewed widely as having become a cumbersome bureaucracy that had lost its sense of focus and responsiveness to the people it served. In 1990, the State Education Department began a stem to stern redesign of the system, including an overall reorganization of the management of all services to people with disabilities in the department and a renaming of the program to the Office of Vocational and Educational Services for Individuals

with Disabilities (VESID). Though lengthy, the new name is more aligned to a new philosophy of service. That year, a serious and long-term redesign of the state VR system began.

The Use of Quality Management Strategies

If there is any government service that can benefit from the use of quality management tools and improved business practices, it is the vocational rehabilitation system. The tools to identify process improvements, redesign systems and procedures, and install continuous improvement measures should become an integral part of the everyday "business" of administering and delivering VR services. No systematic redesign should be undertaken, nor will it result in true systemic change, unless it is supported by a solid strategic management plan and redesign tools.

With the help of IBM and the Xerox Corporation, the VESID management team was able to receive substantial training on the use of quality tools and to set up a Quality Support Team structure to assist regional offices in institutionalizing continuous improvement practices. Without this initial attention to training and long-term support, our redesign efforts would not have been as successful.

Phases of Redesign

The redesign of the state agency's VR system was conducted in three phrases.

Mr. Gloeckler is Deputy Commissioner, New York State Education Department, Office of Vocational and Educational Services for People with Disabilities.

The first phase focused on improving access to the program, one of the most problematic aspects of the system according to consumers and referring agencies. The intent was to refocus the consumer/counselor relationship and to build much stronger collaboration with other agencies. The goals were simple:

- Provide services to individuals as quickly as possible.
- Simplify the steps in the process of entering the vocational rehabilitation system.
- Provide the highest quality services possible.

Did it work? Chart A shows the dramatic increase in referrals, applicants, and people determined eligible for services.

Applications were made simpler. The consumer became a primary source of information about his or her own needs and goals. Unnecessary evaluations, which had become a part of the "culture" of the system, were eliminated.

Phase II of the redesign effort focused on improving the quality of the delivery of services to consumers. No traditions were sacred. An internal task force

was established which identified aspects of the service delivery process that impeded or delayed individuals from having successful outcomes. An external advisory council worked with the internal task force to identify priorities for Phase II. They were:

- Increase integrated employment opportunities.
- Institute performance based contracting focusing on outcomes.
- Consolidate contracts.
- Improve educational linkages.
- Increase access to higher education.
- Initiate regional service planning.

Each priority was managed by a team, consisting of staff from the central and regional offices, other relevant state agencies, and consumers of service. In addition, 366 external stakeholders were involved in drafting the teams' recommendations. Three thousand copies of the draft recommendations for reform were distributed to consumers; local agencies; professional organizations; educational institutions; business, industry, and labor groups; and advocacy organizations. More than 500 people returned comments on the

recommendations for change. There is no question that stakeholders were involved in this phase of redesign from the outset. The recommendations that were adopted affected virtually the entire service delivery system.

Phase III of the redesign effort addressed the entire array of VESID's internal processes. New redesign teams (comprised primarily of counselors, with representation of clerical staff) were formed, with particular emphasis on applying quality tools to improve our internal processes. The teams used the information gathered over the first 3 years of reform efforts and interacted with stakeholders to establish a plan with two goals and a set of critical success factors for each.

Goal #1 is: Develop a service delivery system that is *consumer responsive* and enables us to provide quality services leading to productive and meaningful employment for all eligible consumers within our human and fiscal resources.

The critical success factors for this goal are:

- At a minimum, 20,000 consumers each year in jobs in the most appropriate and integrated settings possible.

Chart A. VESID Referrals, Applicants and Eligible Consumers Federal Fiscal Years 1990–1996

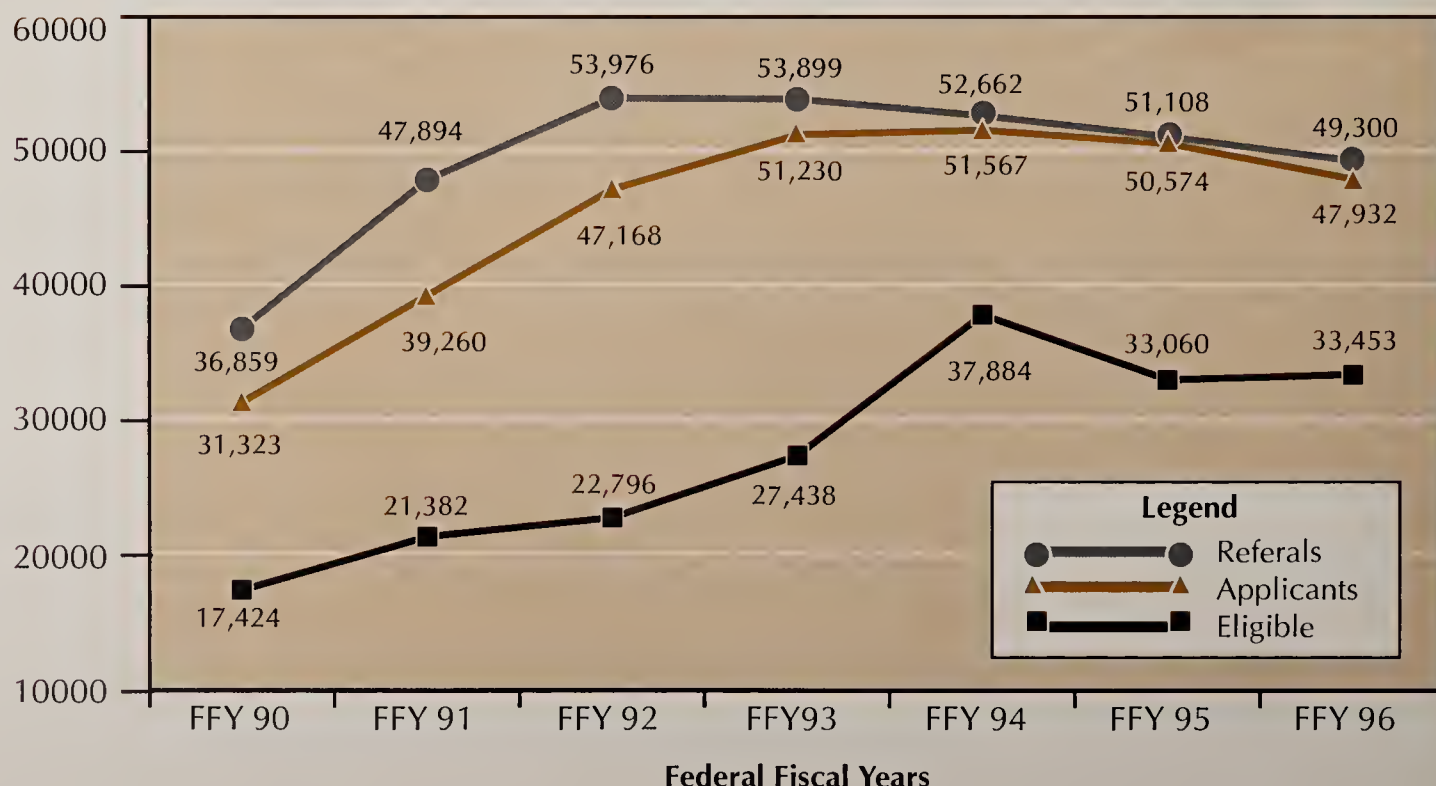
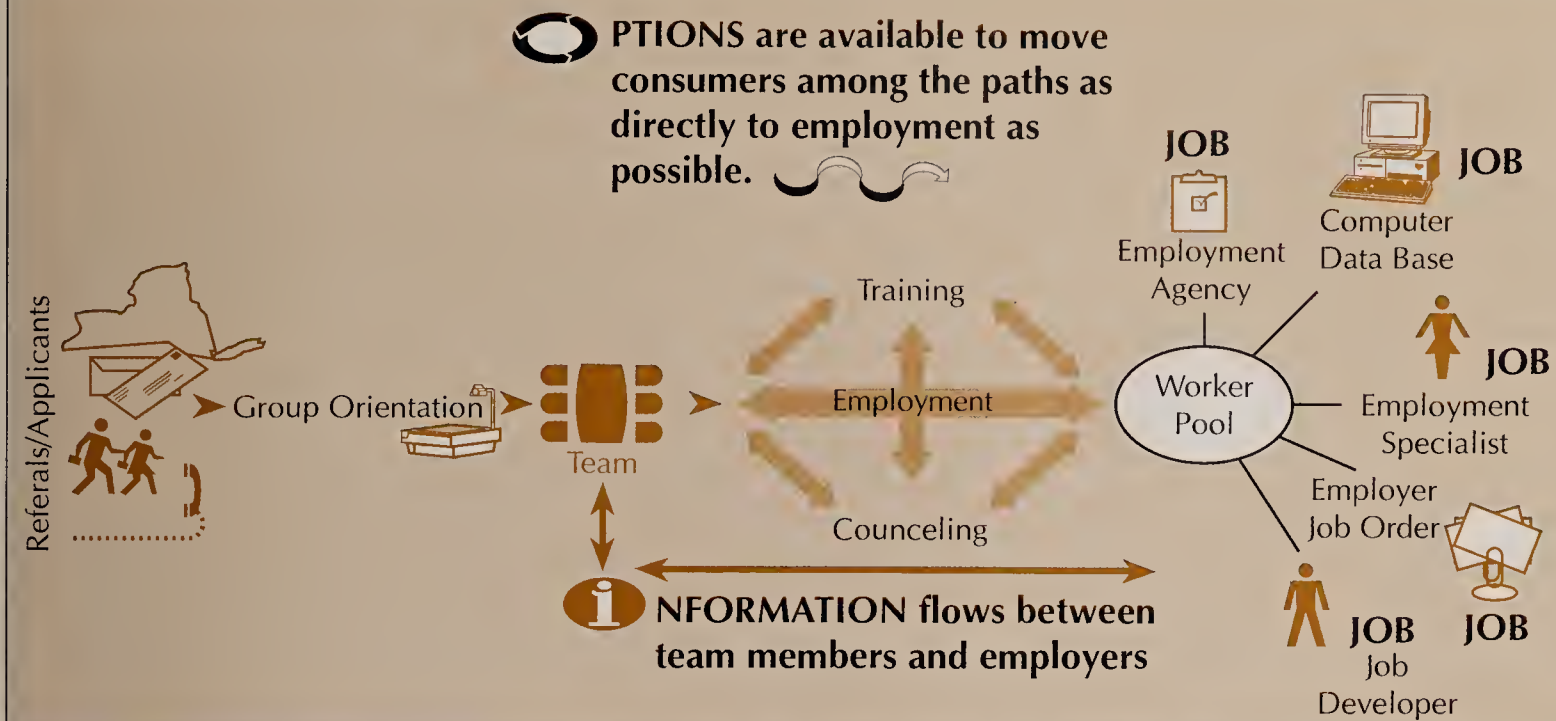


Chart B. Blueprint for Improved Services



- One hundred percent consumer satisfaction rate with VESID services, processes, outcomes, and interactions with VESID staff.

- Recaptured human and fiscal resources redirected to help greater numbers of consumers obtain productive work.

- Skills and abilities of staff maximized to better achieve outcomes consistent with the needs of consumers.

- Human and fiscal resources directed to achieving integrated employment outcomes.

- Cost-effective use of space, technology, and administrative services to support service delivery.

- Consumer access to appropriate job opportunities at any stage in the service delivery process.

- A focus on securing appropriate employment outcomes as quickly as possible for all people with disabilities, including those with the most severe disabilities.

- Individualized services to meet consumer needs; consumers will not be required to accept a "package" of services.

- Convenient access to vocational rehabilitation services.

Goal #2 calls for the development of a service delivery system involving the

public and private sectors that is *employer responsive* and maximizes cooperation in planning, implementation, and resource allocation.

The critical success factors for Goal #2 are:

- A regional network configuration that enhances employment outcomes, reduces duplication, and enhances interagency and intra-agency cooperation, resource sharing and support consistent with the needs of the region.

- The regional network, comprising public and private sector representatives, will increase the number of jobs developed annually.

- The system will respond to an employer's request for assistance in filling a position within 2 working days. Previously our best efforts resulted in a 2-week response time.

- One hundred percent employer satisfaction rate with VESID and regional job development, placement, and support services. Today, in an office that has completed most of its redesign, employer satisfaction is above 90 percent.

- The regional network will maximize a cost-effective use of space, technology, and administrative services to support the delivery of services to consumers.

The plan for redesign of VESID's service delivery system represented significant differences in the structure and function of the VESID system and the way people with disabilities and employers experience it.

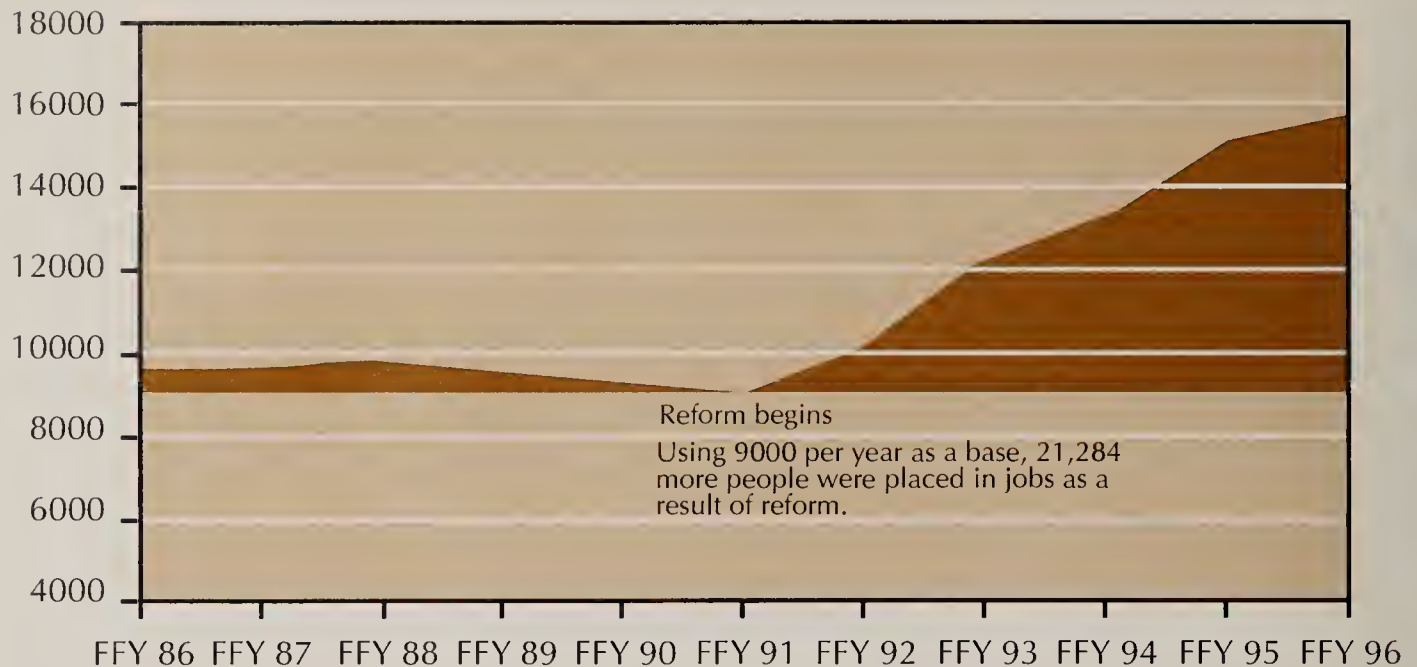
The Results of Redesign

The key to any redesign effort is to establish key performance indicators and to track data on these measures. Collecting timely data on employment outcomes, timeliness and cost effectiveness of service, staff productivity, and consumer satisfaction will tell you if your process improvements are making a difference and when and where to make adjustments.

Chart B depicts a new schema for the delivery of vocational rehabilitation services developed by the redesign teams. It shows:

- an easier application process;
- closer connections to schools;
- group orientations that are more efficient and effective than past practices;
- a team approach to serving the consumer that is more efficient for both the consumer and staff;

Chart C. Impact of VESID's Reform Efforts



- more options for the consumer to move to employment as quickly as possible;
- a highly focused outcome on employment; and
- greater dialogue with and attention to the needs of employers.

Chart C describes how the reform effort directly affected results. When we set

the goal of 20,000 placements annually nearly everyone said that it was too high, and that it was unattainable. We are now close to two-thirds of the way toward our goal; and we will get there.

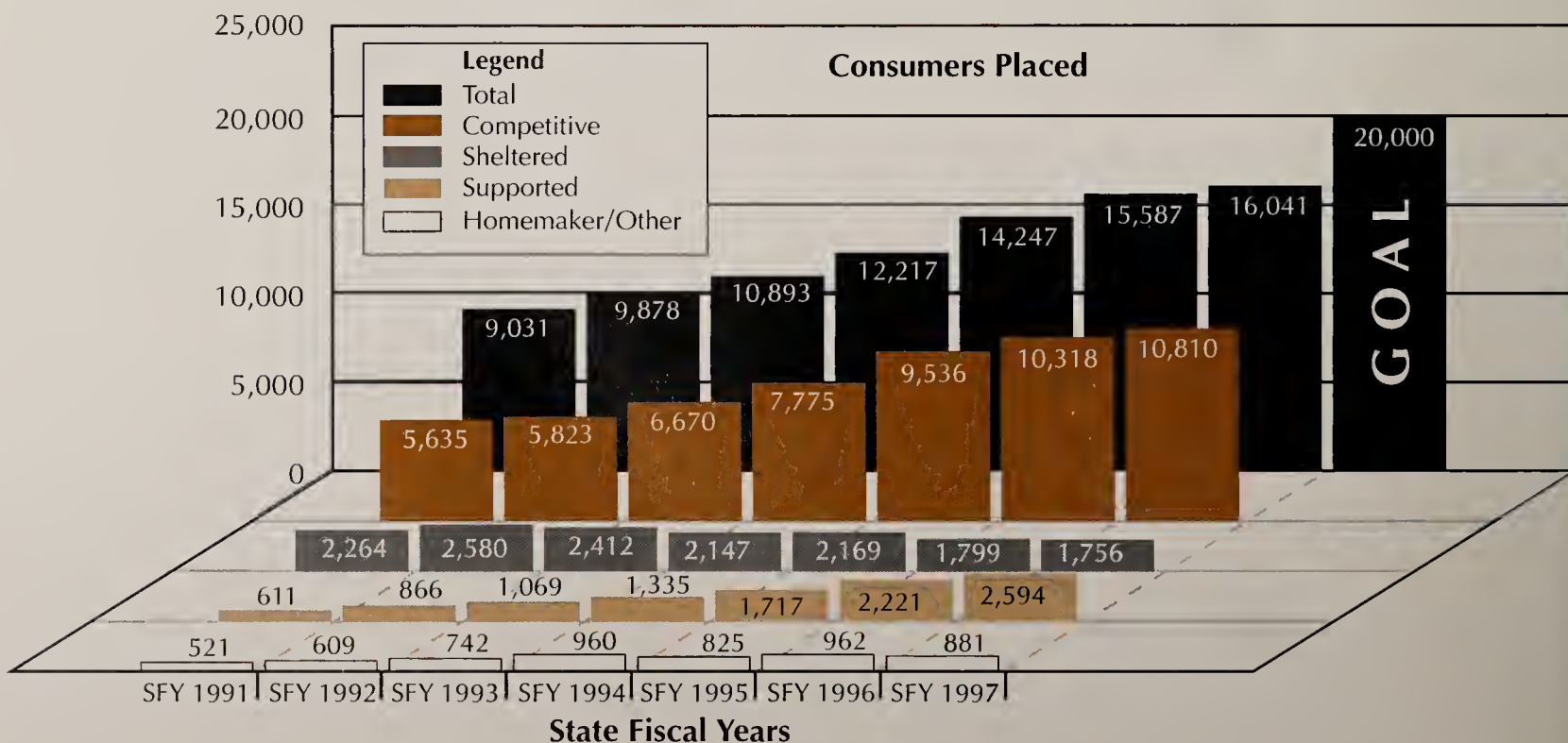
Chart D shows how redesign has led to an alignment of resources and results with the goal of increasing integrated employment options and placements.

Employment Outcomes

The following are other highlights of data which measure the change the redesign effort has effected:

- Total placements have increased 77.6 percent since 1991. In this same period, competitive placements have increased 91.8 percent and supported

Chart D. Consumers Placed



employment placements have increased 324.5 percent, while sheltered employment placements have decreased 22.4 percent. During this same period, the percentage of people with severe disabilities placed has increased.

- The total first year earnings of the 16,041 people with disabilities who were successfully placed in state fiscal year (SFY) 1996 was \$171 million. Using the approximately 9,000 per year as a base, more than \$75 million of this total can be attributed to reform efforts in SFY 1996. The cumulative increase in first year earnings during the reform effort has now reached \$128 million. Similarly, of the \$19 million in public assistance that was saved as a result of the 16,041 job placements, more than \$14 million of these savings can be attributed to reform efforts during SFY 1996. The cumulative impact saved through reform efforts is \$83 million.

- Increasing numbers of people applying for services were found to be eligible. In federal fiscal year (FFY) 1990, only 56 percent of all applicants were found to be eligible for VESID services, while 69.8 percent of all applicants were found to be eligible for services in FFY 1996.

- In FFY 1996, an average of 4,108 individuals were referred to VESID each month, a 34 percent increase in monthly referrals since FFY 1990.

- The number of people applying for services has grown by 53 percent,

from 2,610 per month in FFY 1990 to 3,994 per month in FFY 1996.

- In FFY 1995–96, eligibility determinations averaged 91 days, compared to 6–18 months in 1989–90, despite the fact that the total active caseload had increased 88 percent and the number of vocational rehabilitation counselors had decreased by more than 10 percent due to a state hiring freeze.

- The transition between schools and vocational rehabilitation has become more streamlined for students. A case review conducted in late June 1995 showed that maximum use was made of school records to determine eligibility in 97 percent of the cases.

Customer Satisfaction

For the last 2 years, VESID has annually surveyed approximately 15 percent of its consumers, active and closed cases. Even with a more than 80 percent increase in active caseload and more than 10 percent reduction in counseling staff, customer satisfaction overall remains at 87 percent. Consumer satisfaction approaches 95 percent in the two offices where the team approach to vocational rehabilitation counseling has been implemented. Also, local surveys are conducted which ask both consumers and employers how VESID is delivering on the requirements that are important to that customer. For example: *Was the information helpful? Were*

you treated well? Was the building accessible? Would additional office hours be helpful to you?

This consumer input is a major force in directing redesign efforts. It is a simple, but easily forgotten principle that organizations, especially public agencies, need to continually remind themselves whom they serve. When we ensure that our customers are satisfied we reaffirm our commitment to their trust.

Cost Effectiveness

- Interagency collaboration with the Office of Mental Retardation and Developmental Disabilities (OMRDD), Office of Mental Health (OMH), and the Commission for the Blind and Visually Handicapped (CBVH) has resulted in approximately \$46,240,000 being made available from these state agencies for supported employment in SFY 1995–96, compared to \$14,460,000 in SFY 1990–91. In addition, VESID funding for supported employment has increased from \$9,145,000 to \$21,246,000 during this same period.

- As of the current state fiscal year, \$13.42 million from evaluation services that traditionally were dedicated to sheltered employment placement programs has been redirected to programs that lead to placement of individuals into integrated settings.

- The average cost per consumer for vocational rehabilitation services over

Chart E.

Type of Exam	SFY 1990	SFY 1994	SFY 1997	1990-96 Change	Cost Savings
General Medicals	8,172	618	120	-98%	\$255,808
Speciality Medicals	4,134	2,221	1,075	-73%	\$294,800
Psychological Medicals	6,428	5,687	4,777	-27%	\$171,749
Total Savings Redirected to Case Services for Other Consumers					\$721,908

the past 4 years has dropped from \$1,320 per consumer in FFY 1994 to \$1,054 in FFY 1996. The decrease has resulted from an effort to approve more cost-effective performance based programs for consumers and the implementation of an internal budgeting system in VESID that focuses on accountability.

- Eliminating the need for repetitive evaluations of consumers allowed \$721,908 to be redirected to other services.

Chart E provides specific data which indicate that reliance on existing documentation reduced the need to request new and sometimes duplicative general and specialized medical exams for purposes of determining eligibility.

What was Learned from the Redesign Efforts?

Having undergone 6 years of redesign and continuous improvement, what was learned that might be of value to others?

1. *It never ends.* Know from the start that you'll never get to the ideal state. Try hard to get to the point where continuous improvement tools and strategies become an organizational way of doing business.

2. *You need a vision that you collectively believe is right.* You will need that as a lens to continuously check to see if redesign efforts are delivering the intended results.

3. *You must invest in staff development.* The people on the front lines need the most support; they can most quickly apply the benefits of their training. However, managers must be trained first, or they will be able to offer little long-term support to staff.

4. *Your customers are your reason for being.* You must meet their needs. Consumers and employers are the primary customers. You need to focus your efforts on satisfying their requirements for specific outcomes and services and you must attend to their need to have them delivered in a manner which is timely, reliable, and courteous. While staff are important internal customers to many of the work processes, they are not the primary customer. If you adopt

this viewpoint, what a difference it will make in your decisionmaking.

5. *Invest in technology.* Staff must have the tools to work smart and be more efficient. Don't expect that demanding it will make it happen. Supporting greater effectiveness is as important as expecting it.

6. *Involve your stakeholders from the start.* Redesign efforts will always require changes in policy and procedures. What seems like a good idea internally may have unintended consequences externally. You need to have stakeholders help improve upon initial thinking and to alert you to improvements that could be made that you would never have considered on your own.

7. *Set high expectations for performance.* Don't be surprised if the initial reaction is negative. High expectations can be threatening to people and organizations, but low expectations are harmful to people and organizations. Redesign must be a vehicle to improve results, not just make work easier.

8. *Collect data on key indicators and publish it widely.* Don't be afraid to publish the bad as well as the good. The purpose of collecting data is not to make you look good, but to discover where your opportunities to improve are and to get the baseline for that next improvement.

9. *Use key data to drive day-to-day operations.* Important information on key indicators can help frontline staff to truly understand how they are doing and where they need to improve. Identify data with which to track the critical milestones in the vocational rehabilitation process — e.g., time from application to eligibility, time to develop an individual plan, and time from completion of training to placement in work. Make this data readily available in a clear and understandable format so counselors and supervisors can use it on a regular basis to monitor their own work.

10. *Invest your resources in performance,* not in the amount of service being provided. There is not enough money allocated to vocational rehabilitation and there never will be. Target your resources on results.


11. *Benchmark the processes you are trying to improve.* Many best practices can be

found within your own organization. It is easy to overlook this in favor of "outside experts." When staff are undertaking projects to improve the way they work, expect them to check with others within the organization on the ways in which they are doing business. Not only do you share the best work of staff, saving others from reinventing the wheel, it is a good way to recognize and reward those who have already accomplished improvements. Also, there is no logic in government benchmarking *only* within government. Get fresh ideas from the best in whatever aspect of your business you are redesigning.

12. *As you collect data and track trends, don't be uncomfortable marketing your successes.* If you want support for your program and your redesign efforts are benefitting your customers in clear, measurable ways, let others know. Vocational rehabilitation is an investment in people. It's the best kind of investment there is. If you truly improve your program by improving its benefit to people, you have a wonderful story to tell.

Conclusion

Any service system that is still using age-old traditions as core processes is a system that is antiquated and experiencing diminishing effectiveness. People in New York State demanded that the vocational rehabilitation system be redesigned and streamlined. This has resulted in an ongoing effort to improve the state VR program. This redesign has proven to be very timely with the recent federal legislation on welfare reform. The rehabilitation system will need to respond to increased demands to serve more people within compressed timelines.

Significant improvement has been made in the program, but many problems still exist. Since the redesign effort must be based on the needs of customers, which change over time, it must be a *continuous* pursuit of a better way to do business. 

The Agreement to Streamline the Public Vocational Rehabilitation Process

Elmer C. Bartels

The agreement between the Rehabilitation Services Administration (RSA) and the Council of State Administrators of Vocational Rehabilitation (CSAVR) to streamline the public vocational rehabilitation service delivery system grew out of a CSAVR initiative following the reauthorization of the Rehabilitation Act in 1992.

Preparing for the reauthorization, a major task force of the council reviewed all known criticisms of public vocational rehabilitation in order to ascertain which "shortcomings" could be alleviated or corrected by the Congress in amending the Rehabilitation Act.

What the task force found was that the vast majority of criticisms were not of the Act or the statute, but rather were leveled at the public service delivery system, little of which is provided for in the statute. The vast majority of concerns were facets of the delivery system which were the result of years of practice, state and federally-imposed requirements, auditing safeguards, and others.

This exercise made it plain to CSAVR that the service delivery system, which had been in existence for more than 76 years, had become a major impediment and an onerous obstacle to the central purpose of the statute—to train and place in competitive employment eligible persons with disabilities.

Determined to remedy this troubling situation, the council convened a 3-day retreat in 1993 at the Aspen Institute for Humanistic Studies on the Eastern Shore of Maryland. The conferees, which included state administrators, RSA representatives, rehabilitation educators, and lawyers, were given the

charge of taking the delivery system totally apart and building it back, piece by piece, into a streamlined system which would facilitate outcomes, while being both customer-friendly and—equally important—user-friendly. As a result of this meeting, many of the state agencies have implemented streamlining initiatives.

The council agreed upon a set of principles designed to increase the numbers of people with disabilities going to work. At the same time, an equally important integral goal was improving the timeliness and quality of service and the nature and quality of jobs obtained by the customers served by the public program.

It became clear that, in order to fully implement the intent of the streamlining initiative, CSAVR, its member state agencies, and RSA needed to agree on some fundamental changes in policy and practice.

The resulting document, *Recommendations for a Model Service Delivery System for Public Vocational Rehabilitation*, outlined four steps in the delivery of vocational rehabilitation (VR) services: (1) Eligibility Determination, (2) Vocational Planning, (3) Provision of Employment Services, and (4) Job Placement.

The conferees concurred that the case review and reporting structures should enhance and support these four steps. It was also noted that the status

system has become a basic part of the VR process but actually does not exist in law and is therefore a creature of regulation, policy, and/or practice. Hence, the status structure could be changed to meet the contemporary demands of a more responsive service delivery system.

It became clear that, in order to fully implement the intent of the streamlining initiative, CSAVR, its member state agencies, and RSA needed to agree on some fundamental changes in policy and practice. Two of the most significant changes were in the areas of case review and reporting. The first affects counselor practice in all of the 50 states, and the latter has reinforced the rigid status structure that has served to impede the provision of timely and effective services.

To fully understand the implementation of the streamlining agenda, it will be useful to review the actual agreement.

The first statement relates to its purpose:

In order that the public vocational rehabilitation program will assist more eligible people with disabilities to obtain real jobs at real wages.

The supporting vision is further stated:

The future of the Public Vocational Rehabilitation Service Delivery System is dependent, in part, upon streamlining the Public Vocational Rehabilitation Service Delivery System to work in partnership

Mr. Bartels is Commissioner of the Massachusetts Rehabilitation Commission.

with consumers to achieve meaningful employment outcomes. The primary focus of this effort must be the achievement of gainful employment outcomes in integrated settings rather than a focus on process.

The agreement goes on to say:

Over the past 2 years, The Rehabilitation Services Administration (RSA) has assisted these State Agencies in carrying out streamlining activities. These streamlining efforts sought to identify practices and policies impeding the rehabilitation process and outcomes from the perspective of consumers, advocates, and rehabilitation professionals.

Recognizing the need to simplify "process" requirements throughout the nation's Public Vocational Rehabilitation System, the RSA in collaboration with the CSAVR commits to a national effort designed to facilitate consumer-responsive, high quality efficient Public Vocational Rehabilitation outcomes. Many of the "process" requirements generally considered to be impediments to an efficient, responsive system have evolved over time and have become institutionalized in the Service Delivery System. To facilitate an effective National Streamlining Initiative, State Vocational Rehabilitation Agencies will be asked to undertake a review of current Agency practices and processes. The Rehabilitation Services Administration will provide Technical Assistance and resources to assist State Vocational Rehabilitation Agencies in these streamlining efforts. Additionally, the RSA commits to ensuring that Federal Regulation and Policies to minimize "process" requirements and support a clear focus on quality employment outcomes.

Further, the RSA commits to incorporate this philosophy into its monitoring practices. Comprehensive Monitoring will focus on areas of concern identified by consumers in individual states.

The RSA and CSAVR Streamlining Initiative represents a joint commitment to ensuring a clear focus on quality employment outcomes for people with disabilities.

The success of the Streamlining Initiative is rooted in a philosophy of a consumer-driven, outcome-based system of Public Vocational Rehabilitation.

Moreover, the scope of the agreement was defined:

Each of the steps to implement the above Vision has specific Actions associated with them and dates by which they are to be accomplished.

The CSAVR and RSA commit their respective resources to the accomplishment of these Strategies and Actions within the time deadlines agreed upon. These actions and time frames recognize the opportunity at hand and the significance of timely implementation.

It is also important to recognize that the CSAVR and Member State Vocational Rehabilitation Agencies are prepared to assist, through the availability of State Vocational Rehabilitation staff, in the work on specific action steps.

This streamlining effort is a joint effort between the RSA and the CSAVR which will require appropriate and available Federal and State staff time and expertise.

The RSA and CSAVR will encourage all State Rehabilitation Agencies to review the plan with their Rehabilitation Advisory Councils, and other stakeholders, to seek their involvement in, and support of, this plan and its implementation in the State Agencies.

It was further agreed that a very specific workplan was needed to bring the streamline agenda to life. The specific objectives and action steps were:

1. Promote State Vocational Rehabilitation Agency self-evaluations in order to identify and promote the adoption and use of policies and procedures that result in a Streamlined Service Delivery System focused on "employment outcomes."

ACTION: The CSAVR will notify all member state vocational rehabilitation agencies of this agreement and recommend this as an opportunity for each agency to further streamline its service delivery with the support and technical assistance of RSA and with the involvement of stakeholders in the review for its planning and implementation.

ACTION: RSA staff will provide support and technical assistance to state

vocational rehabilitation agencies for the purpose of streamlining the vocational rehabilitation service delivery process in each state agency.

ACTION: The state rehabilitation directors will develop regional support networks, facilitated by each CSAVR regional representative, to work collaboratively in support of the region's individual and collective State Streamlining Initiatives.

ACTION: RSA recognizes that state agencies may, as appropriate, implement this Streamlining Plan utilizing resources from the 1.5 percent set-aside which is required for uses described in Section 123 "Innovation and Expansion" of the Rehabilitation Act.

2. Commit personnel and discretionary resources, including the Regional Rehabilitation Continuing Education Program (RRCEP) and In-Service Training, to achieve the Streamlining Objectives.

ACTION: The RRCEP's will be directed to provide training and technical assistance to state vocational rehabilitation agency staff that are tailored to the needs of the region and the state which adopt the streamlining agenda.

3. Focus on the important steps in the vocational rehabilitation service delivery process: Eligibility, Employment Planning, Service Implementation, and "Employment Outcome."

ACTION: The RSA Commissioner will issue a clear and concise Policy Statement on streamlining to RSA staff and State vocational rehabilitation agencies, defining the new Four-Step System and requiring its use. RSA will provide adequate lead time for state vocational rehabilitation agencies to implement changes in reporting requirements in a consistent, uniform and accurate manner. The Policy Statement will be written to support caseload management and the new Streamlining Initiative.

ACTION: CSAVR will work with RSA to establish the Priority of Issues to be addressed under Policy Streamlining.

4. Utilize the recommendations of the "RSA-CSAVR Section 140 Work Group", when relevant and appropriate, to establish a Statistical and Fiscal Reporting Sys-

tem that supports an employment outcomes-oriented service delivery system and the RSA/CSAVR Streamlining Initiative.

ACTION: Revise the RSA-113 Cumulative Caseload Report, (PD-95-03).

ACTION: CSAVR will share the *Streamlining Strategies* with the CSAVR members of the "Section 140 Work Group" and request them to develop a work plan and to recommend and develop proposed report changes and instructions, in order to address the goals of the *Streamlining Initiative*.

5. Maintain and utilize the collaborative State-Federal Vocational Rehabilitation Monitoring System, including the Case Review Instrument, to assure compliance with the law and consistency with the RSA-CSAVR Streamlining Initiative.

ACTION: Adopt the new Monitoring System.

ACTION: Adopt the new Case Review System focused on employment outcomes.

ACTION: Train reviewers in the utilization of the Monitoring System and the Case Review Instrument in order to reflect the new *Streamlining Initiative*.

ACTION: The CSAVR/RSA Task Force on Monitoring and Case Review will review the RSA Monitoring System and

make recommendations from the states' perspective that will enhance and support the *Streamlining Initiative*.

ACTION: CSAVR's comments in response to the *Vocational Rehabilitation Notice of Proposed Rulemaking* (NPRM) will include a proposed definition of "substantial services" with supporting rationale.

6. Assure that the RSA State Plan Requirements and Policy Directives are consistent with the RSA/CSAVR Streamlining Initiative and reflect on outcomes.

ACTION: RSA will take steps to assure that State Plan Requirements and Policy Directives developed are consistent with the law, regulations and the *Streamlining Initiative*.

ACTION: CSAVR will develop model eligibility and Individualized Written Rehabilitation Program (IWRP) forms which reflect the new *Streamlining Initiative* and the experiences of states which have implemented streamlining.


7. Utilize the Institute on Rehabilitation Issues (IRI) and other effective approaches as vehicles for the continuous refinement and enhancement of improved employment outcomes through the state-federal vocational rehabilitation program.

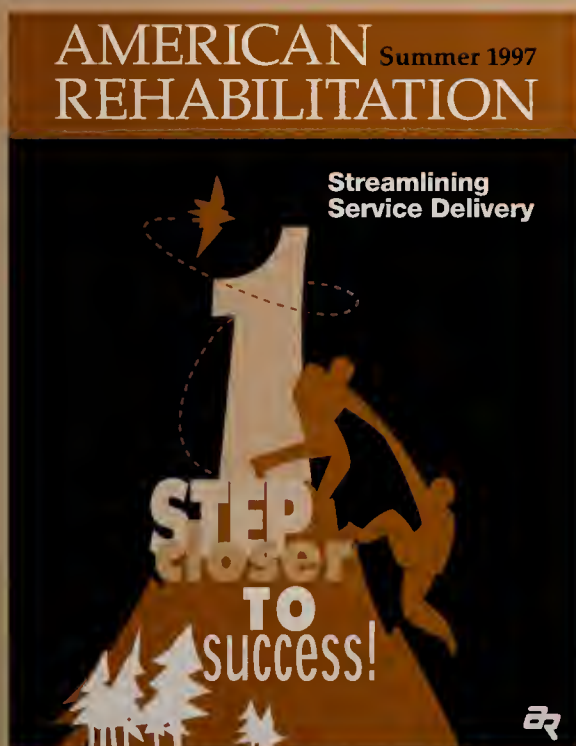
ACTION: RSA and CSAVR will identify and communicate proposed

streamlining issues to the IRI for study and development of useful guidance and training materials in order to sustain, expand, and improve the *Streamlining Initiative*.

Conclusion

In reviewing the entire effort to streamline the vocational rehabilitation process, the agreement between CSAVR and RSA proved to be an important tool for communicating the overall purpose. Specific individual objectives themselves assured that the necessary underpinnings to the agreement were in fact in place.

It is a compliment to the Council of State Administrators of Vocational Rehabilitation, the individual directors in each state, and to the Rehabilitation Services Administration and its commissioner that this overall improvement of public vocational rehabilitation occurred. There is no other state vocational program of any type that has seen the joining of federal/state officials for the purpose of improving the service delivery process. It is a compliment to all of the parties involved that such an initiative was conceived and implemented in such a timely fashion over the period of just a few years. 



If you find in **American Rehabilitation** the kind of material that informs or that is useful to you in some way, a colleague who does not receive the magazine may also profit by it. If you know such a person, fill out the blank below and send it to Editor, **American Rehabilitation**, Room 3212, 330 C Street, S.W., Washington, DC 20202-2531. We will be happy to send your friend a sample copy of the magazine.

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NEW PUBLICATIONS AND FILMS

No Dignity for Joshua. More Vital Insight Into Deaf Children, Deaf Education and Deaf Culture.

Tom Bertling. Kodiak Media Group, P.O. Box 1029-K054, Wilsonville, OR 97070. FAX: (503) 625-4087. Softcover, 110 pages, \$21.95 plus a handling fee of \$4.95.

A followup to the author's previous book, *A Child Sacrificed to the Deaf Culture*, this book was also written especially for parents of deaf children, deaf educators and administrators, and those having a professional or social interest in deaf people. Chapters include "Sexual Abuse at Residential Deaf Schools," "The Militants and a Culture Fractured," "The Fiery Deaf Language and Education Issues," "Grim Realities Inside a Deaf World," "Cochlear Implants in Young Deaf Children," and "Hearing Injustices."

Pegged Down. Experiences of people in Ireland with significant physical disabilities.

Jean Tubridy. Institute of Public Administration, Publication Division, Vergemount Hall Clonskeagh Dublin 6, Ireland. Telephone: (01) 269-7011. FAX: (01) 269-8644. Softcover, 266 pages, £8.99.

Rehabilitation Counseling. Profession and Practice.

Springer Publishing Company, 536 Broadway, New York, NY 10012-3955. Telephone: (212) 431-4370. FAX: (212) 941-7842. Hardcover, 392 pages, \$46.95.

Addressing modern technology and paradigms, as well as the information needed for contemporary professional rehabilitation practice, *Rehabilitation Counseling* focuses on the basic knowledge and skills essential for counseling and other professional services. In

the last decade the rehabilitation disciplines witnessed great changes and substantial growth, which effected professional practice of the altering its goals, clientele, and public endorsement of programs. This book provides comprehensive guidelines for rehabilitation professionals and students, including basic information about the profession, persons with disabilities, professional practice, social values, and impact on recipients.

Consumer & Family Guide to Quality Services.

CARF... *The Rehabilitation Accreditation Commissioner, Employment and Services Division*, 4891 East Grant Road, Tucson, AZ 85712. Softcover, 76 pages, \$20. Tele: (520) 325-1044 (Voice/TDD). FAX: (520) 318-1129. Web Page: <http://www.carf.org>

Written with the consumer and his/her family in mind, this publication provides information on exploring the available service options and provider organizations. It explains the accreditation process and what is meant by quality services. Each type of service listed in this guide is followed by a service description highlighting the values that help ensure the provision of quality services. Following the service description is a list of questions the consumer may want to ask potential service providers.

Managing Outcomes. Consumer-Driven Outcomes Measurement & Management Systems. A Guide to Development and Use.

CARF... *The Rehabilitation Accreditation Commissioner, Employment and Services Division*, 4891 East Grant Road, Tucson, AZ 85712. Softcover, 67 pages, \$35. Tele:

(520) 325-1044 (Voice/TDD). FAX: (520) 318-1129. Web Page: <http://www.carf.org>

This monograph is intended as a guide to the field in addressing the CARF standards and outcomes and information management and as an aid to the development of feasible, usable outcomes information systems. While simple in their approach, the four-component system and six-step implementation process presented here reflect a fundamental premise of the CARF ECS standards: consumer input is crucial to achieving good outcomes, and use of outcomes information for quality improvement is essential to maintain a program's quality. The framework and suggestions presented here are not specifically required by the CARF standards, but they do provide a framework for the design and management systems that conform to the intent of the CARF standards.

The numerous specific suggestions contained in this monograph have been contributed by many individuals and organizations involved with CARF. To that extent, the ideas and best practices have been generated by CARF's customers.

Outcomes Management in Behavioral Health. Outcomes Management Systems. A Guide to Development and Use.

CARF... *The Rehabilitation Accreditation Commissioner, Employment and Services Division*, 4891 East Grant Road, Tucson, AZ 85712. Tele: (520) 325-1044 (Voice/TDD). FAX: (520) 318-1129. Web Page: <http://www.carf.org>

The purpose of this monograph is to help an organization develop and implement a quality outcomes management system and use the information

obtained to continuously improve its delivery of services. This document has been developed for persons or organizations that have realized the importance of obtaining and using information related to effectiveness and efficiency of their services. The material contained in this publication goes beyond CARF's actual standards for outcomes evaluation in the Behavioral Health standards and serves as a guide that provides instruction, suggestions, and best practice methods for use in designing, implementing, and using a full outcomes management system consistent with CARF's mission, purposes, vision, values, and standards.

Mental Ills and Bodily Cures. Psychiatric Treatment in the First Half of the Twentieth Century.

Joel Braslow. *University of California Press, 2120 Berkeley Way, Berkeley, CA 94729. Tele: (510) 642-4562. Hardcover, 254 pages, \$40.*

This book depicts a time when physicians attempted to heal the mind by treating the body with methods we might now find extreme and perhaps even brutal. From a treasure trove of California psychiatric hospital records, including many verbatim transcripts of patient interviews, the author reconstructs this "therapeutic" world of mental patients and their doctors, a world composed of drastic somatic treatments such as hydrotherapy, sterilization, electroshock, lobotomy, and clitoridectomy.

Children with Disabilities. Fourth Edition.

Mark L. Batshaw, M.D., Editor. Paul H. Brooks Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624. Tele: (410) 337-9580. FAX: (410) 337-8539. Hardcover, 926 pages, \$49.95.

Since it was originally published, *Children with Disabilities* has been used as a medical textbook for students in a wide range of disciplines, addressing the impact of disabilities on child development and function. It has also served as a professional reference to special educators, general educators, physical therapists, occupational ther-

apists, speech-language pathologists, psychologists, child life specialists, social workers, nurses, physicians, advocates, and others providing care for children with disabilities.

Learning Disabilities and Employment.

Paul J. Gerber and Dale S. Brown, Editors. pro-ed, 8700 Shoal Creek Boulevard, Austin, TX 78757-6897. Tele: (512) 451-3246. FAX: (512) 451-8542. Softcover, 400 pages, \$36.

Divided into four sections, this volume contains 18 articles by some 26 professionals in the field of learning disabilities. Part I, "Employment of People with Learning Disabilities: The Big Picture," includes four articles/chapters; Part II, "Training Persons with Learning Disabilities for Employment," is covered in six chapters; Part III, "Workplace Issues," contains five chapters devoted to this specific topic; and Part IV, "Experiences in the Workplace," has three chapters on this subject.

Although specifically written for persons concerned with learning disabilities, this text should prove useful to all professionals in the broad field of rehabilitation who are involved with placing persons with disabilities into competitive employment.

Torticollis. Differential Diagnosis, Assessment and Treatment, Surgical Management and Bracing.

Karen Karmel-Ross, Editor. The Haworth Press, Inc., 10 Alice St., Binghamton, NY 13904-1580. 124 pages. Softcover, \$19.95; hardcover, \$39.95.

For pediatric physicians, orthopedists, surgeons, physical therapists, occupational therapists, and family physicians, this book provides a systematic approach to the assessment and treatment of congenital muscular torticollis as well as vital information on torticollis and its impact on the growth and development of children. It covers the differential diagnosis of this disorder, its conservative management, the advantages of a team approach to management, the selection of appropriate treat-

ment techniques and pathways, and the relationship between torticollis posture and development of postural control and balance.

Interactive Staff Training. Rehabilitation Teams that Work.

Patrick W. Corrigan and Stanley G. McCracken. Plenum Publishing Company, 233 Spring St., New York, NY 10013-1578. Hardcover, 273 pages, \$47.50 (U.S.), \$57.00 (foreign). Tele: (212) 620-8047 or, toll free, 1-800-221-9369. FAX: (212) 807-1047. Web Page: <http://www.plenum.com>

This book was written for members of the rehabilitation team: counselors, social workers, assistants, psychologists, nurses, physiatrists, activity therapists, etc. Although the focus is on the development of rehabilitation programs for adults with severe mental illness, training strategies in this book are transferable to other problems and populations where the intervention is conducted by a team.

Assessing Medical Rehabilitation Practices. The Promise of Outcomes Research.

Marcus J. Fuhrer, Editor. Paul H. Brooks Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624. Tele: (410) 337-9580. FAX: (410) 337-8539. Hardcover, 469 pages, \$67.

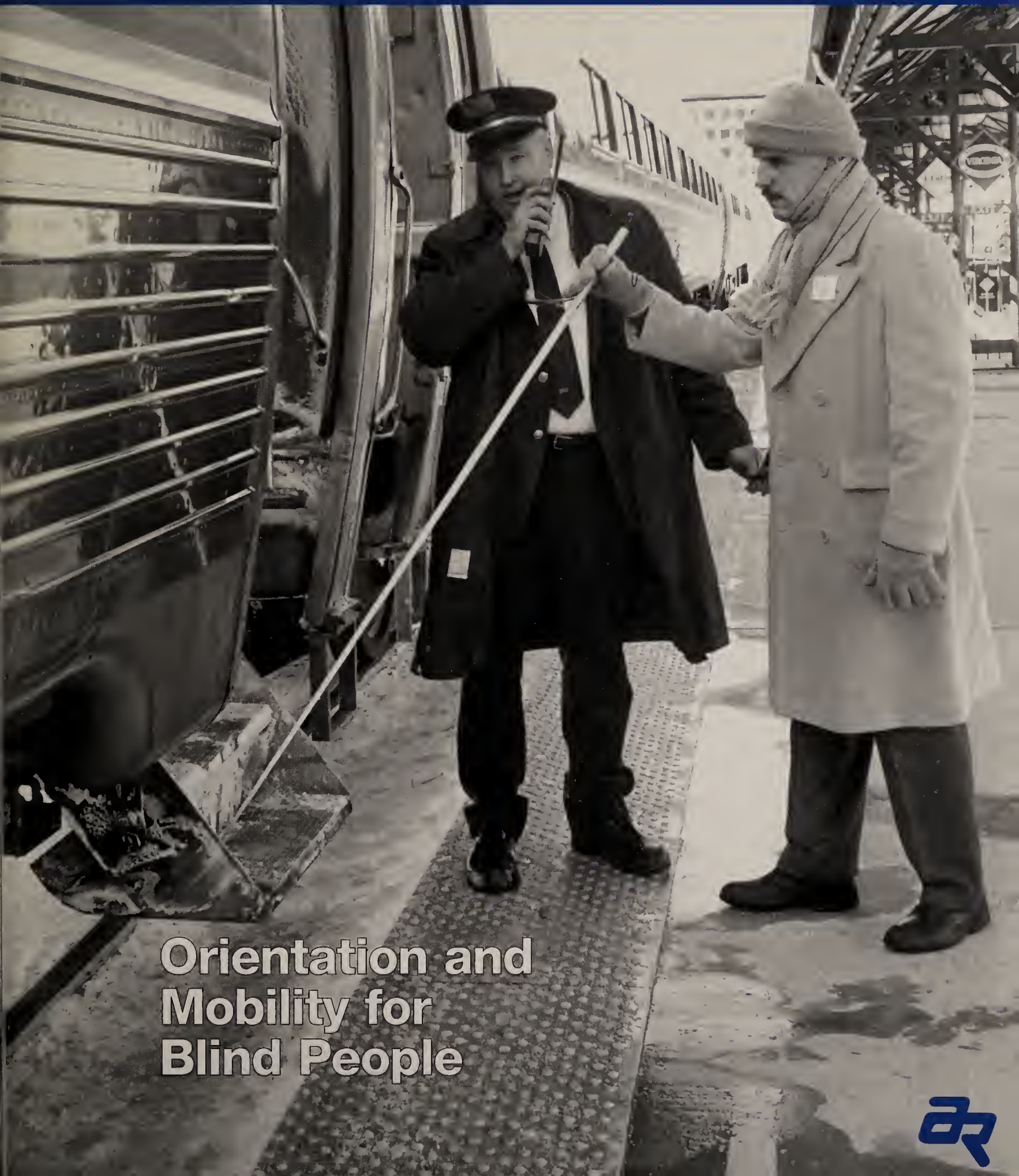
Authored by a group of distinguished researchers, this volume examines cross-cutting issues and appraises the status of outcomes research for specific musculoskeletal, cardiovascular, and nervous system conditions such as stroke, arthritis, heart disease, brain injury, spinal cord injury, cerebral palsy, and amputation. It offers scientific evidence for use in developing and maintaining effective practices, highlighting critical economic considerations, and it provides recommendations for future research that will strengthen the case for appropriate medical rehabilitation services—benefits that serve researchers, physicians, therapists, nurses, social workers, healthcare administrators, payers, and, ultimately, consumers.

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**Orientation and
Mobility for
Blind People**



Implications of Final Regulations on O&M Instruction

Fredric K. Schroeder

Commissioner,
Rehabilitation Services Administration



The final regulations implementing the 1992 Amendments to the 1973 Rehabilitation Act, as amended, require state vocational rehabilitation (VR) agencies to include, as part of that agency's state plan, policies and procedures to establish and maintain a comprehensive system of personnel development designed to ensure there is an adequate supply of qualified rehabilitation personnel, including professionals and paraprofessionals, available to meet the rehabilitation needs of that state agency.

Section 361.18 of the final regulations and, in particular, paragraph (c) (1) (ii) of this section, is especially relevant to VR agencies serving the blind when considering the employment of qualified personnel for the provision of orientation and mobility (O&M) services to blind people. More specifically, this requirement in the final regulations is especially applicable to the concerns many state agencies have with regard to the issue of hiring blind O&M instructors.


Many state VR agencies as well as many community rehabilitation providers currently employ blind O&M instructors who are successfully providing vitally needed rehabilitation services to blind individuals. However, since national certification standards pertaining to the O&M profession have historically required the presence of normal vision in order for an instructor to meet these standards, blind instructors have historically been prohibited from obtaining national certification due to their disability. As stated in the preamble discussion of Section 361.18, "The Secretary is cognizant of the particular difficulty experienced by blind individuals who, historically, have been excluded on the basis of their disability from becoming certified as O&M instructors. The Secretary emphasizes that these regulations do not inhibit designated state units (DSU's) or other VR

service providers from hiring blind individuals as O&M teachers even though those individuals may not meet current certification requirements. To the extent that a DSU employs blind individuals who do not meet the 'highest requirements in the State' applicable to the O&M profession, the state agency's plan under paragraph (c)(1)(ii) of this section must identify the steps the agency plans to take to assist employees in meeting these requirements."

The preamble discussion further mentions that if the current certification standards for this or any other rehabilitation profession are discriminatory on the basis of disability, the standards should be reviewed for compliance with Section 504 of the Rehabilitation Act and with the Americans with Disabilities Act.

When considering revised certification, licensing, or registration standards as they apply to blind O&M instructors which would meet the "highest requirements in the State," as set forth in Section 361.18 paragraph (c)(1)(ii), a

state VR agency could develop and adopt standards which do not require the use of vision of visually-based functional abilities, or the use of a sighted assistant as a condition for certification, but would otherwise require a blind instructor to qualify as an effective O&M instructor in all respects. One proposed alternative teaching method, which does not rely on the use of vision as an essential component of its basic instructional style, has proven to be effective and is currently being successfully practiced by many blind O&M instructors in the field. This teaching methodology is known as the "discovery model" of teaching and is based on the principles which have been drawn from cognitive learning theory. This model of cane travel instruction utilizes discovery methods of learning to develop a sense of trust and self-reliance on the student's own internal feedback system as a way of assessing one's travel performance, rather than relying on guided teaching techniques. Since the *discovery model* relies on internal feedback from environmental cues and self-monitoring techniques, vision would not be required as an essential part of the job qualifications and, therefore, blind individuals would not be excluded from qualifying as O&M instructors under certification standards incorporating the model.

The following articles are being presented here to assist state VR agencies in gaining a better understanding of this alternative teaching method used by blind O&M instructors and to also stimulate further creative thinking in the field regarding the use of various teaching approaches which can be applied in a variety of environmental settings, such as in rural and urban travel and in specialized situations, such as in the case of the elderly-blind and the deaf-blind. 

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The weakest ink is better than the strongest memory.

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Cover Photo: Steven Hastalis, Customer Assistance Representative at the Chicago Transit Authority, Chicago, IL, boards the Virginia Railway Express train at L'Enfant Plaza, Washington, DC (*see article on page 31*).

U.S. DEPARTMENT OF EDUCATION
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Beyond City Sidewalks

the blind traveler in a rural environment

Douglas Boone
Christine Boone

The teaching of orientation and mobility to persons who are blind continues to be an evolving profession. In January of 1929, the Seeing Eye established a dog guide training school at Morris Town, New Jersey, providing the first formalized travel training program for blind adults. After World War II, the long cane gained wide acceptance as an effective travel tool as well. Today, orientation and mobility instructors provide training to blind people of all ages, in environments ranging from large metropolitan areas to small towns. Those of us who work in the profession constantly strive to provide our students with the most comprehensive travel training available, enabling them to participate fully in employment, family life, and community activities. One area of mobility training which remains somewhat uncharted, however, is that of rural and recreational travel.

While many working age blind people choose to live in urban areas in order to avail themselves of public transportation and other services, many of the senior blind, along with a significant number of children and working age adults, make their homes in rural settings. Additionally, some of our nation's most inviting vacation spots lie at the edge of civilization and beyond. As blind people play an ever increasing role in the mainstream of society, they find themselves needing or wanting to travel independently and skillfully in rural and even untramed places. Through our own experiences, both as instructors and travelers, we have developed some effective techniques which enable blind people



to travel freely while living, working, and recreating "far from the madding crowd." Before elaborating on these methods, it might be helpful to examine the framework into which these techniques are laid.

Many of you are familiar with the *discovery learning* approach to orientation and mobility instruction. An ever increasing number of professionals in the field of work with the blind are adopting this teaching method with exciting results. Students who engage in discovery learning tend to possess greater confidence and can apply their skills in a wider range of travel settings. Dr. Allan Dodds, in his book, *Mobility Training for Visually Handicapped People: A Person-Centered Approach*, clearly distinguishes between the "authoritarian" style of instruction and the "egalitarian" instructor, who employs the discovery learning method (Dodds, 1988). The benefits of this approach to cane travel instruction are far too numerous to detail in this article. However, a brief explanation seems appropriate.

The discovery learning approach simply involves instruction through the use of problem solving and information seeking techniques rather than route travel and rote memorization. This method teaches the student to evaluate his or her surroundings and apply the transferable skills of travel, using dog or long cane, to the situation at hand. Discovery learning requires us to make some basic assumptions about our students. The student is presumed capable of collecting information which is present in the environment such as sound cues, tactile variations, use of the sun and or wind, and other environmental attributes that may be present. Blind travelers must learn to recognize, evaluate, and incorporate all of this environmental information if they are to be effective travelers. The average blind person, if given an opportunity to experience the benefits of discovery learning, has no difficulty in meeting this challenge. Discovery learning is further characterized by instructor guided questioning of the student to assist in finding a solution. When a student encounters chal-

lenges in the course of a lesson, no answers are provided. Instead, the instructor asks him or her to assess and utilize information readily at hand, nurturing the student's ability to solve problems. As a result, the student also learns to evaluate his or her own technique and take corrective action when necessary. Students who successfully master travel through discovery learning travel independently and successfully in new areas as well as familiar ones. They also deal easily with unexpected obstacles such as construction, poor directions, or inclement weather.

The advent of the discovery learning method is especially applauded by blind business persons whose jobs often involve extensive travel. Their careers are enhanced and in some cases even facilitated through the use of these travel techniques. The rural traveler is particularly well served by the discovery method of learning. Since rural areas are certainly not consistent, the flexibility and problem solving ability that accompany this approach are essential to independent travel on the farm or in the wilderness.

Choosing The Cane

We believe that it is the instructor's responsibility to recommend a specific cane and provide reasons for that endorsement. Recommendations should be based upon teaching experience and the experiences/opinions of blind travelers. Our selection of a cane is based upon our own field testing, during years of instruction, together with the opinions of countless former students.

We find the rigid, hollow fiberglass cane to be the most versatile tool for overall use in traveling. This lightweight, flexible cane arcs easily when held loosely in the hand, causing minimal fatigue to the wrist and fingers. A round metal tip completes our ideal cane, sliding easily through tall grasses, without catching or sticking. The metal tip also produces excellent auditory information when used on hard surfaces while tending to glide over rough areas and small cracks. The solid fiberglass cane, also with a metal tip, shares many

of the same advantages as the hollow counterpart. It takes second place in weight, being approximately three times heavier, increasing wrist fatigue. In the area, of durability however, the solid fiberglass cane ranks superior: It is almost indestructible.

Efficient, safe travel is best achieved when using a cane that reaches to chin height in almost all cases. After the student develops speed and confidence, additional length will be added. We find support for this length of cane (*Foundations of Orientation and Mobility*, 1980) in a short, but insightful reference to the value of the extra length:

On this whole subject uninitiated members of society are often vocal in behalf of "a totally blind man I know who never had any lessons and does beautifully." And indeed individuals have done down through the ages. The most noted of these was an Englishman named John Metcalf, who in the 18th century was a road builder and performed authenticated feats of getting about by himself on foot and on horseback, once guiding a sighted individual through a bog in dark of night. His doings were regarded by his contemporaries and by succeeding generations as little short of marvelous. To the present they are less so, for an old print shows he had a cane so long it was almost up to his hat. This instrument foreshadowed the principle on which one type of formal instruction was to be built when it finally arrived (Mannix, 1911).

We find that the extra cane length allows for a more natural positioning of the cane, while providing additional response time when encountering obstacles in the environment. The confidence gained from locating obstacles in ample time to react, without panic, is

Mr. Boone is Director of the Pennsylvania Bureau of Blindness and Visual Services, Harrisburg, PA; Ms. Boone is an associate with the law firm of Stokes & Murphy, Atlanta, GA.

very important. This is no small consideration when treading the less traveled path!

We include a brief lesson in storing the rigid cane in a car, which allows graceful entering/exiting of an automobile. This simple trick involves placing the cane between the seat and door, with its tip to the front. The cane is then pushed down to lie along the floor where it will not interfere with other passengers climbing in and out. This method takes less time than collapsing a folding or telescoping cane, and it facilitates learning by encouraging the student to take the cane on outings, using it in a variety of travel situations.

Rural (Country) Travel

When introducing travel skills in a country setting, where dirt or gravel roads are the norm, it is just as important for new rural students to develop consistency in basic cane technique as it is for their urban peers. Grip, cane position, width and height of the arc, and keeping in step should be taught and practiced in an area near the person's residence, until confidence has developed. During the course of the lessons on basic technique, we introduce an awareness of available environmental information. While continuing to stress consistency in the mechanics, we are laying the groundwork for future use of such cues as sun, wind, and traffic sounds.

Many people in rural areas are accustomed to using cardinal point directions. When someone becomes blind, the knowledge that the barn is north of the house provides a great starting point for an early travel lesson. After mastering the basic cane arc (usually accomplished through repeated trips along a path between the house and driveway), the student selects a building which he needs to locate. At this time, the technique for minimizing entanglement of the cane in tall grass is introduced. Indeed, this simple modification from the usual use of the cane is also effective in winter travel. The student holds the cane in a pencil grip, maintaining a two point touch. The arc is modified by pok-

ing the cane into the tall grass (or snow) and pulling it back out. The procedure is repeated on the other side of the arc, providing for information on the path which lies beneath the grass.

Concurrent with the introduction of the technique for traveling in tall grass, the student learns the value of the sun as an aid to orientation. Here, a simple drill proves most effective. In order to

Students who engage in discovery learning tend to possess greater confidence and can apply their skills in a wider range of travel settings.

utilize sun cues, a traveler must be able to localize the sun while walking. Using cardinal point directions and common knowledge regarding the changing position of the sun throughout the day, the student walks a straight line in a given direction with the sun as a guide. The person is then instructed to stop and turn in a different direction, again using the feel of the sun as a guide. These exercises are repeated frequently during the early days of travel training in the rural setting until the student is adept at orienting him/herself with the aid of the sun. The exercises are not confined to locating only north, south, east, or west but also include northeast, northwest, and so on.

Only after the student is proficient in using cardinal point directions do we introduce a Braille compass. A number of rural travel situations, particularly on a farm, require the combination of landmark location and directional travel. The student may need to find a particular corner post, then walk several hundred yards, northeast, through an open field to locate an irrigation

pump. On a sunny day, the sun can be used. On a cloudy day, our traveler uses a compass to confirm the northeasterly direction while crossing the field and finding the irrigation equipment.

Creating sound cues around the farm offers another useful alternative. Leaving a radio turned on in the barn or toolshed enables the blind farmer to locate each building instantly, facilitating rapid, easy movement from one place to another. The volume needn't be inordinately loud to be heard in the relative quiet of the farm. Hanging tin cans or wind chimes on the irrigation pump works well to create a sound cue in the middle of a field, where using a radio is not practical. While not useful on a day without wind, the chimes should almost always provide at least an intermittent sound cue.

The Country Lane

While learning to travel down a country lane, several pieces of information will assist the blind traveler in maintaining orientation. Ruts or irregularities in the road surface provide a great source of information and should be noted when introducing the student to the lane. The relaxed, confident blind traveler would easily notice the ruts and recognize their value in keeping oriented. The beginning student, by contrast, may feel somewhat overwhelmed, with low self-confidence and high anxiety, necessitating that the instructor draw attention to the seemingly obvious. During that first walk down the lane, sun and wind cues are again called into play and their usefulness stressed as a strategy for maintaining orientation. If a student becomes disoriented, we prefer to ask questions to allow for problem solving to occur. Students who travel in the country, where the population is sparse, must learn to rely on themselves and their own instincts, which are almost unerringly correct. The primary purpose of these first few sojourns is to develop problem solving skills and self-confidence while gaining insight regarding the use of effective travel alternatives. The student is well served

by concentrating on these things rather than worrying about completing the formal "assignment." In keeping with the discovery learning approach to instruction, the instructor's questions become more general as the skill and confidence of the student develops. At the conclusion of training, the student possesses the ability to problem solve independently, correcting mistakes without the aid of an instructor.

Additional information along the lane provides useful assistance. The hard packed tire tracks on the dirt or gravel lane, the lane's edge (usually lined with weeds), and the sound of sporadic traffic in the distance can be effectively used while traversing the lane. Other information in a given setting can be useful if put in context with the route being traveled. The hum of electrical wires along the county road, the rustle of a lone tree somewhere en route and myriad other cues can be used in combination with directional orientation to navigate the country lane.

Out of the Lane, and Down the Road!

The student will benefit from prompting by the instructor regarding the various cues that can be used to locate the convergence of the farm lane with the county road. Encouraging the student to make effective use of traffic, even if sparse, starts during the first lesson by prompting him to listen to the distant approach of any vehicle passing by on the county road. The sound of cars traveling along the road tells the student exactly where that road is located and draws an auditory line, marking the direction in which the road leads. The instructor also provides specific information regarding the change in the texture underfoot as the lane meets the county road. If it is a dirt lane meeting a gravel county road, the transition is immediately obvious. Where both roads are gravel, turning and passing cars will cause the gravel to form a pile at one side or in the center of the intersection. These piles of gravel will many times be accompanied by a slight slope and/or a well



worn, hard packed tire track. Learning to use this information warrants taking as much time as the student needs to discern the distinguishing characteristics of the intersection. This information will be used to find other lanes along the county road and will enable the traveler to locate his own lane on the return trip.

In rural America, cars traditionally drive down the middle of the road, moving to the right only when meeting oncoming traffic, or perhaps at the crest of a hill. When walking down a rural road, the accepted pedestrian rule concerning facing oncoming traffic will, out of necessity, be set aside. The blind traveler should gather certain information about his destination before setting out along the county road. This information is almost identical to that required by a sighted traveler. How many roads lie between his lane and the destination? Which way must he turn

upon arrival? The successful traveler must walk on the side of the road where he will find the intersecting road for which he is looking. In this way, the blind country traveler can easily locate his turnoff.

To locate another residence down the gravel county road a combination of compass direction, sun cues (if available), distance, time required in walking to the destination, and changes in the gravel (the piling mentioned earlier) will assist in finding a neighbor's lane. Also useful is the disappearance of weeds along the road just prior to or concurrent with an intersecting lane. Other pieces of information may be present and by questioning the student, such things as the smell or sound of barnyard animals, the sound of an air conditioner, the smell of a furnace which has just turned on, provide useful cues.

What about going from the county road to a hard surface road such as blacktop or pavement? Along a busy road of this type there generally exists an edging or shoulder that is suitable for walking along. The shoulder may be dirt, gravel, or an extension of the blacktop road surface. If the shoulder is gravel or dirt and in good repair, the student can walk approximately a cane's length from the edge of the road surface. The student will quickly discover that being too far away from the road leads to encounters with weeds and washouts, while being too

Efficient, safe travel is best achieved when using a cane that reaches to chin height in almost all cases.

close will cause the passing cars to honk or otherwise respond in a less than positive fashion. This problem is solved by dividing the distance between the edge of the road and the grass line. As with travel in the city, the sound of traffic appearing in the distance, passing alongside, and fading away is used to assist orientation when traffic is present. If the road surface is continuous with the shoulder, then it is a simple task to occasionally arc to the side near the grass or weed line to maintain a reasonable distance from the parallel traffic. In a few instances, the road surface can extend to what can only be termed a ditch, not suitable for walking. This poses a problem for both the sighted and blind pedestrian and raises the question of safety. Each situation should be carefully considered, with the test for safety being the same for the blind pedestrian as for the sighted. The fact is, a few areas exist where it is simply not safe for *anyone* to walk along the roadside.

The Small Town

Travel in a small town, where no sidewalks exist and streets are predominantly gravel, requires use of some of the approaches previously described for traveling in the country. Time, distance, direction (using the sun), the transition of one street to another resulting in piles of gravel, slopes of the tire tracks, and the hard packed gravel where the cars usually drive are some of the cues which might be used. Ask your students to tell you when they get to an intersection by using some of the cues discussed previously. Additionally, some of the information found in larger cities can be employed in the rural small town. Teaching the student to note the sound change and the feeling of things opening up enables that student to know when he or she reaches the intersection. There may also be some prominent or subtle landmarks that the student may choose to use. Mail boxes, sidewalks leading from houses to the street, driveways, and, perhaps, wind chimes are just some of the landmarks which might be avail-

able. By working a given route several times, focusing on identifying useful cues and *permanent* landmarks, the student is empowered to apply the same technique when exploring other routes independently. Again, the discovery method allows students to become practiced in analyzing situations, separating useful information from the general surroundings, and using that information to assist them in finding their destination.

Finding specific businesses in the downtown area of a small town is not unlike locating stores in a shopping mall. The sound of closing car doors, pedestrians' foot falls as they step in and out of stores, and odors from a bakery, bar, feed and grain, or hardware store provide blind travelers with a wealth of information about the shops they pass on their travels. A particular business is located in much the same manner as it would be in a larger town or city.

In some small towns, paved streets may exist but no sidewalks paralleling the street are present. In this case, the traveler walks along the edge of the street, using the parallel curb as one source of information. We encourage the student to utilize the sun and the sound of traffic, if present, in combination with the tap of the cane against the parallel curb. Assuming the student is on the left side of the street, he/she should walk in or near the gutter and maintain a good arc with the left swing of the cane encountering the curb. In cases where the student will be walking several blocks without needing

to locate a particular address or street, the left arc need only contact the curb every three or four steps. Constant *shorelining* is not necessary for most students and, if used full distance, tends to slow the rate of travel. Shorelining may also focus the student's attention on the curb and away from other more important bits of information in the environment. As the student nears an intersection, the open space of the converging street results in an "opening up," where the sound is markedly different and more wind movement is felt. Additionally, streets in the country (as well as in town) are crowned in the center, sloping down to the curb or edge on either side. This kind of road surface facilitates runoff when it rains and it is also easily detectable by the blind traveler. The road dips slightly as the traveler approaches an intersection, then rises gradually as he or she crosses the intersecting street.

Locating a specific residence along either the gravel or paved street is a matter of knowing how many streets need to be crossed, the side where the residence is located, and the approximate position of the residence in the block. To confirm location of the correct address, landmarks (which are best discovered by the student, not the teacher) can be helpful. As previously discussed, these landmarks will vary from situation to situation.

The Recreation Side of Travel

An interesting but challenging request came from one of our students who lived along the Oregon coast. In Oregon, all beaches are public domain and, while it is possible to own property set back from the beach, a significant expanse of beach/sand dunes may separate a residence and the ocean's edge. Such was the case of one cane travel student who wished to walk to the beach and then take walks along the ocean edge. A path, of sorts, led from his home through the dunes to the beach. The student's travel skills were good, so getting to the beach was not a problem. Returning was another matter! The shifting sand where the

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high tides contacted the sand dunes effectively eliminated the use of land marks. He had tried hanging wind chimes but these were either blown down or removed by someone walking along the beach. The solution was found in a talking clock with a time elapse feature. As the student left the convergence of the trail and the beach, he started the clock. He then walked a desired amount of time away from the trail. When he stopped and turned to come back, he checked his clock to see how much time had elapsed. He then walked back toward the trail for the same amount of time as was spent going away from the trail. We found that this system allowed him to stop very close to the trail on his return and all that was needed was a systematic check with the cane in order to locate the trail. The one variable, in addition to walking at the same gait, that needed to be taken into account was the occasional encounter with another beach walker. It was important to pause the clock when this occurred to account for the time spent talking. Numerous trials were conducted and all resulted in success, with the student enjoying recreation in the form of a solitary stroll.

Many blind travelers enjoy hiking through a wood or along a rugged mountain trail. The techniques employed in hiking and packing will vary somewhat, depending upon the terrain involved. Woodland trails are generally fairly smooth, broken by occasional roots or rocks but otherwise flat. In walking these trails, most blind hikers find it helpful to maintain a normal cane arc while keeping the cane on the ground as it moves back and forth. Thus the traveler easily detects objects protruding from the ground and can step over them.

The rocky mountain trail offers quite a different challenge. Here the ground often lies completely hidden beneath rocks and boulders. In such a setting, the pencil grip works well. The traveler uses the cane almost as he/she would when climbing stairs, arcing it back and forth directly in front to judge the position of rocks and find a foothold. When traversing steep or rocky trails,



blind hikers also use their feet to feel the terrain beneath them. This enables them to maintain balance while climbing.

Because we love the Colorado Rockies and the beautiful high mountains of New Mexico, we often find ourselves in areas where feet and hands are both required to scramble up a steep incline. Here, having a chain or chord on one's cane is helpful as the traveler can simply loop the chain over his/her wrist, letting the cane slide along behind, while negotiating that part of the trail. We do not recommend folding or telescoping canes for hiking along rugged trails. The sturdiness of the straight cane is far more dependable in the uneven, unpredictable areas that comprise our national parks and wilderness. We have also concluded, through trial and error, that a cane with a rounded metal tip works best when hiking or packing. The nylon tip lodges easily in crevasses between rocks and sticks in the soft dirt of a woodland path. By contrast, the metal tip tends to glide over these places and seldom causes a jam.

A Braille compass should also be part of the hiker's standard equipment. Although not an absolute necessity, the compass provides valuable information on the direction of travel, enabling the traveler to quickly set a course in the opposite direction for the return trip. On a sunny day, the direction of one's travel is easily maintained, but after sundown or on a cloudy day, the compass is especially helpful. The recreational traveler should also include a folding cane in his/her pack. When the day's plans include horseback riding or canoeing, the straight cane can remain in camp, while the folding cane rides easily in a pocket or backpack as the traveler paddles downstream or sits astride a horse. The folding cane also provides a backup if the straight cane should break during a trip.

When following a woodland or mountain trail, one generally begins and ends at the trailhead. The trails either wind in a complete circle or reach the summit, at which you turn and retrace your steps to the starting point. Before embarking on a trail walk, the blind hiker, like his/her sighted counterpart, should get some information about the trail. How long a walk is involved? Does the trail form a circle, or must one walk to the end and return along the same path? Do other trails branch off from the main path? The blind traveler must take careful note of the surroundings at the trailhead since he/she will need to recognize them upon his/her return. This is not difficult as the trailhead usually widens into a more developed area such as a parking lot, visitor's center, or large clearing. While proceeding along the trail, the traveler should keep track of the movement of the sun (if it is shining), the rise and fall of the terrain, and the amount of time spent on the trail. These factors, together with the use of a Braille compass, can assist the hiker in keeping track of his or her location during the hike. If other trails branch off from the main route, blind and sighted hikers alike must locate each fork as they travel to facilitate a safe and speedy return trip.

Another area in which a blind vacationer might find him/herself could



include a rushing stream or a quiet but swiftly flowing river with a cozy and secluded cabin nearby. We visit just such a spot every summer and it offers unique and spectacular venue for solitary morning walks and fishing expeditions. This little cabin is located in the midst of a pristine wilderness. In fact, the National Forest Service recently designated the area as such under the Federal Wilderness Act and the cabin is the last human habitation between that point and the headwaters of the Colorado River.

The first step in orienting oneself to this kind of setting involves a thorough exploration of the area immediately surrounding the cabin. It is important to note the terrain and any prominent landmarks within 20 yards or so of the building. This exercise works best when the blind person explores alone. In this way he/she can become completely fa-


miliar with the area before striking out along the footpath that leads deeper into the mountains. Walking down to the river is the next step.

When walking toward or along a body of water, the blind traveler must use a good cane arc at all times. Sometimes a smooth sandy beach precedes the water and sometimes the water itself makes a lapping, gurgling, or rushing sound. In these instances, the traveler receives ample information regarding his proximity to the water. At other times, however, the water flows quietly along and lies directly at the bottom of a rocky slope. Such is the case at our mountain retreat. In fact, tiny inlets run into the bank under the grass and a number of hikers, blind and sighted, have stepped in one and taken an unexpected swim in the chilly Colorado. Again we find that a pencil grip works best here, and, because of the hidden inlets, the cane must firmly contact the ground at every step. This is not always easy, as fallen trees, rocks, and undergrowth blanket the steep slope. However, with an hour of practice the technique soon becomes second nature.

Sound travels much further in the wilderness than in town, providing an excellent travel tool for the blind explorer. A radio left on the porch can be heard at a great distance. We can also preserve the silence and simply sing out a greeting when we know we have drawn near. The answering shout will leave no doubt as to the location of the cabin. The talking clock (mentioned

earlier) can be used here as well. Keeping time on the trip upstream can enable the hiker to accurately determine when he/she reaches the vicinity of the building. The earlier exploration then quickly pays off and one is able to locate the entrance easily.

We simply cannot address in one article all of the recreational travel activities in which blind people participate. The body of literature in this area remains small, but as more blind travelers discover the pleasures of country travel, we look for this to change. For some excellent tips on fishing and related matters, we suggest "Hook, Line and Golf Balls," by David Walker, *The Braille Monitor*, (July 1995).

Unfortunately, some professional orientation and mobility instructors, together with members of the general public, remain unaware of the relative ease with which blind people can and do travel in rural and recreational areas. We hope that our teaching experience, guided as it was by enthusiastic, adventuresome blind travelers, will benefit our colleagues as much as it has enhanced our own instructional abilities. When an instructor begins with the premise that the blind student possesses the ability to travel independently, given the right tools and training, that confidence flows to the student. Through discovery learning and problem solving, the student learns to rely on himself and trust his instincts. The techniques outlined herein enable blind travelers to successfully navigate the millions of square miles of land that lie beyond the city sidewalks. 

***On a sunny day,
the direction of
one's travel is easily
maintained,
but after sundown
or on a cloudy day,
the compass is
especially helpful.***

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Orientation and Mobility for Deaf-Blind People

Dona Sauerburger

Very few programs specifically serve people who have both a visual and a hearing impairment, even though this combination produces unique situations requiring unique strategies and solutions. Instead, people who are deaf-blind must seek services from programs that serve deaf people or blind people and which usually have staff who are prepared only to serve one or the other. The frustrations and fears that this situation causes both professionals and deaf-blind people are legion.

Orientation and mobility (O&M) specialists are no exception. Even though, at one time or another, most of them will work with people who are both blind and deaf, many feel inadequate about doing so. I remember the first time a deaf-blind person was referred to me. I told the counselor that because I had not been trained to work with such a person, he should refer her somewhere else. Fortunately, the counselor convinced me that I had the skills needed to work with this woman. Indeed, teaching O&M to her was one of the most rewarding experiences of my professional career, inspiring me to become more involved and to work more with deaf-blind people.

O&M specialists can rest assured that if they know the O&M skills needed by people who are visually impaired or blind, they already know most of the O&M skills that are needed by people who are also deaf. To teach those skills and provide appropriate services to their deaf-blind clients, O&M specialists need to know: (1) strategies for com-

municating with that client (such as using an interpreter); (2) how to teach that client to communicate with and interact with the public; and (3) street-crossing strategies for clients who cannot hear the traffic adequately.

Communication with the Client

Knowing how to communicate with a deaf-blind client involves much more than just knowing a communication system such as fingerspelling or signs. Without knowing about the client's background and culture, the O&M specialist won't even know what language that client may be using, much less what communication strategies would be appropriate for him or her.

There are some deaf-blind people who have no formal language because they were never exposed to a language in a mode that they can perceive, or they have a cognitive impairment that prevents them from being able to process language, or both. More information about communicating and working with people who have minimal language skills can be found in Baumgart, Johnson, and Helmstetter (1990), Godfrey and Costello (1995), and Huebner, Prickett, Welch, and Joffe (1995).

In general, however, the primary language of Americans who are deaf or deaf-blind is either American Sign Language (ASL) or English. ASL is the primary language for many people who are born deaf. By this I don't mean that they use a visual mode, such as signs or written notes, to communicate in English, but rather that their native language is ASL, which has its own grammar and sentence structure. They may or may not be skilled in the

use of the English language itself, regardless of whether it is written or spelled out, conveyed with signs, or spoken, because English is a second language for them.

Because ASL and English are different languages, a person whose language is English (such as most American O&M specialists) and one whose language is ASL (such as many congenitally deaf, visually impaired Americans) may have difficulty understanding each other. For example, to someone who understands only ASL, the English sentence, "John will teach Bill after they eat their lunch," may be understood to mean that they will have the lesson before lunch. Conversely, that same sentence in ASL, "Lunch finish; Bill John teach," may be confusing to someone whose only language is English.

Deaf people whose language is ASL vary in their level of comfort and skill using English. For some, English that is spelled, written out, spoken, or signed will be adequately clear and understood; for others, it will lead to confusion and misunderstandings. Thus, it is important to know whether the client is congenitally deaf and, if so, in what language(s) he or she is proficient. If the client is proficient only in ASL and the O&M specialist's only language is English, an interpreter will be necessary in order to provide clear, full communication.

Whether the deaf-blind client's language is ASL or English or neither, there is a wide variety of communication techniques and devices that are

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available. The choice of which technique should be used with a given client, and whether that client will best perceive the communication tactually, visually, or auditorally, will depend on the client's vision, hearing, primary language, experience, skills, and preferences. The best way to find out which would be best is to ask the client. Some of the available techniques include signs, symbols, signals, fingerspelling, Braille, written notes, speaking, and lipreading; however, if the client does not understand English well, all but the first three techniques would be inappropriate. There are many communication devices that can be used, including the teletouch and Telebraille (on which the speaker types messages that the deaf-blind person can read in braille); homemade cards or commercial plates, such as the Brailtalk, which have Braille and print letters to which the speaker can point or place the deaf-blind person's finger; commercial or homemade "communication boards" with pictures and/or symbols and accompanying print notes to which deaf-blind people can point or on which their finger can be placed, and so on. There are a number of sources of information about communication techniques and strategies to use with deaf-blind people, including College for Continuing Education (1995), Godfrey and Costello (1995), Kates (1980), Sauerburger (1993), and Smith (1994). Whether the communication will be provided by the O&M specialist or an interpreter will depend on the instructor's skills with the method and language of choice.

When an interpreter is used, the O&M specialist and the client communicate with each other rather than with the interpreter; the skilled interpreter will then convey the messages accurately to the other person. The interpreter should be skilled in the communication methods and languages being used and, just as important, he or she should be impartial. Because it is difficult or impossible for most family members and friends to remain impartial, it is strongly advised not to use them as interpreters. Another issue to

consider is that interpreters who are skilled working with deaf sighted people may need to learn how to convey the communication tactually or accommodate for the visual needs of deaf-blind people; it cannot be overstated how important it is to convey visual information to the client, such as describing the environment and what is happening around them, facial

Some of the available techniques include signs, symbols, signals, fingerspelling, Braille, written notes, speaking, and lipreading.

and body expressions of the speaker, and so on. Several good sources of information about using interpreters with deaf-blind people are Bourquin (1996), Raistrick (1995), and Sauerburger (1993).

Communication and Interaction of the Client with the Public

An important part of most O&M programs is teaching people to interact with the public for soliciting aid, shopping, dealing with over-solicitous strangers, and so forth. This aspect of O&M is a challenge when working with deaf-blind people for several reasons: the methods that deaf-blind people need to use to successfully communicate with the public are often unfamiliar to the O&M specialist (and often to the client as well); the public's reaction to people who have a hearing

impairment in addition to a visual impairment is not always the same as it is to those who are only visually impaired; and deaf-blind people are often less able than hearing blind people to understand what is going on around them. This difficulty with understanding what is happening can lead to confusion and misunderstanding, an inappropriate distrust of the public, and a subsequent unwillingness to travel independently wherever there might be any interaction with strangers.

The creative and skillful O&M specialist can help prevent this unfortunate situation by helping deaf-blind clients prepare to communicate with methods that the public will feel comfortable using; helping them realize that the public is usually bewildered and the importance of being persistent and patient to help the public learn how to communicate with them; and providing them with feedback after their experiences with the public. This feedback, if accurate and informative, can help deaf-blind clients learn to interact and understand what may be happening around them at some point in the future when they are alone.

To prepare the deaf-blind client to communicate with the public, the O&M specialist and the client can brainstorm to choose techniques that might be effective and then practice those techniques until the client is proficient. The instructor may not know any more than the client which strategies would be best for which situation; the client and instructor can only guess which might be best, and then try them. If these methods don't work for that person in that situation, then others need to be tried. Because no system is ever successful with every person in every situation, the more techniques with which the client is proficient, the more likely the interaction will be successful; if one attempt fails, the client who is proficient in several techniques can try another approach.

Many clients are tempted to rely on communication techniques with which they are familiar and skilled, but they will instead need to choose and become proficient with techniques which the

public will understand and, perhaps as important, with which the public will be comfortable. Such techniques include using gestures which other people will understand, notes and cards, voice (if the deaf-blind person's voice is understandable), recorded messages (devices such as the *Attention Getter* can record several messages which can each be played repeatedly with the touch of a button), and pictures and symbols. The public can be asked to respond by giving a signal, such as tapping the deaf-blind person, squeezing his or her hand, nodding their head "yes" or "no," or tapping the deaf-blind person's hand twice for "yes" and once for "no"; using their finger to print letters on the deaf-blind person's palm ("print on palm"); spelling out messages or pointing to pictures and messages with the deaf-blind person's communication device; speaking, if the client can understand speech; writing notes, if the client has enough vision to read them, and so on.

Once the client has chosen which methods seem best, he or she will need to become proficient before trying them with the public. Print on palm, like most communication methods, requires practice, and clients can often perceive the print better if they place their hand lightly on the hand of the speller (most strangers do not mind this). People with minimal language skills who are using pictures, symbols, or prewritten notes and cards need to understand what those pictures, symbols, and cards mean. For example, the client who is taught to point to the note next to the picture or symbol of the hamburger needs to understand that it means he or she is requesting a hamburger. People who are taught that when they are lost they are to find an appropriate person to whom they can give their special emergency card need to understand how to use that card and to wait for help to arrive.

The client also needs to understand that the public will need the client's help and patience in order to facilitate communication. Many deaf-blind people assume that the public understands that they are deaf and knows how to

communicate with them. When the public fails to cooperate, these clients—not realizing that the people did not understand what to do—will instead assume that the people are purposely being rude or hateful, and the client may give up in disgust. Other clients whose attempts to communicate fail will wait passively, or continue to use the same communication method for long periods of time without trying another method. The deaf-blind client needs to understand that he or she may need to be persistent and try several ways of explaining to the public such things as how they can communicate or help, and that he or she is deaf as well as blind.

Whether the deaf-blind traveler is using a card, voice, or recording, if the first message is that he or she is deaf-blind, many people will become bewildered or suspicious and will move away without investigating further. Thus, it is helpful to first explain what the traveler needs (e.g., "I want to cross the street," or "I need to know when the bus arrives at Fifth and Maple"). The deaf-blind traveler also needs to decide exactly how he or she wants the public to respond in order to help or communicate, and should explain this clearly immediately after the need is explained ("Please tap me if you can help," "Please hand me this card when the bus arrives," or "Please guide me to the door," etc.). After this information is conveyed, the visual and hearing impairments can be explained ("I am deaf and can't see well," or "I am blind and hard of hearing"). Examples of effective messages are: "Please help me find the bus stop; tap me if you can help because I am blind and can't hear well." "I need to find a salesperson; please print letters on my palm with your finger because I am both deaf and blind."

After clients have become proficient with as many communication techniques as possible and understand the need to be patient and persistent with the public, they are ready to try to communicate and interact with them. At this point, the O&M specialist's role is to step back and observe the interaction unobtrusively. If the public realizes that

the instructor is with the client, they will not behave normally and the clients will never learn whether their strategies are effective or not.

It is relatively easy for instructors to be unobtrusive while observing clients who have learned to travel independently and who are trying their skills in new areas where their instructor has not been observed teaching them. However, instructors who work at rehabilitation centers or who have been working intensely with their client to orient him or her to that area will be challenged to find places to teach the client to interact where the public is not familiar with their role as an instructor, and to observe what happens without being noticed. It may be necessary in some cases to have the interaction observed by an assistant who is unknown to the public, or to observe from a distance, perhaps using a hidden microphone which can enable the instructor to hear what is going on.

After each interaction, the O&M specialist and client debrief the experience. The client needs to learn what the instructor observed, and judge whether it was successful or not. If it wasn't, the client can brainstorm with the O&M specialist to think of strategies that might be more successful and to try them, again, with observation and feedback.

Street-Crossing Strategies

The fact that the deaf-blind client cannot hear well, or at all, can require the O&M specialist to adjust the techniques that are taught, but I have found those adjustments to be minimal in all areas except that of street-crossing strategies. We O&M specialists have learned to teach people to cross streets primarily using their hearing (although many also use their remaining vision effectively), and it often requires some readjustment on the part of the O&M specialist to consider strategies to evaluate and teach people how to cross streets when they are deaf as well as blind or visually impaired.

Basically, the O&M specialist will need to help deaf-blind clients 1) eval-

... it cannot be overstated how important it is to convey visual information to the client. . . .

uate when they cannot hear and/or see well enough to know when it's clear to cross; 2) decide in which situations where they cannot detect the traffic they are willing to take the risk of crossing alone; 3) learn strategies for getting assistance or planning alternate routes for those situations where they do not want to risk crossing alone; and 4) learn how to judge when it is safe to cross and how to complete the crossing safely at intersections with traffic signals where they can hear or see the traffic well enough or see or feel the traffic signal.

At intersections with traffic signals, it is relatively easy for the experienced O&M specialist to evaluate whether clients can observe the traffic flow or traffic signal well enough to recognize when it is their turn to cross. Because the instructor will not be with the clients during their entire lives, it is also necessary for the clients to be able to evaluate whether they can cross safely or not in a variety of conditions at intersections with traffic signals.

At situations where the street being crossed has no traffic signal or stop sign to control the traffic, the O&M specialist can evaluate (and teach the clients to judge) whether or not they can detect the traffic well enough to know when it's clear to cross by using the *Timing Method for the Detection of Vehicles* (Sauerburger, 1989, 1995). O&M specialists can also help clients who can see the traffic at a distance to evaluate their ability to judge when it is slow enough or far enough for them to cross safely by using the *Timing Method for Assessing the Speed and Dis-*

tance of Traffic (Sauerburger, 1989, 1995). Again, it is imperative that all clients, including those who have both visual and hearing impairments, be able to judge for themselves whether they can detect or judge the speed and distance of the traffic well enough to know when it is safe to cross.

People who cannot hear or see the traffic well enough to know when it's clear to cross have to decide whether the risk of crossing there alone is acceptable or not. For example, most deaf-blind people who travel independently consider the risk of crossing their neighbors' driveways to be acceptable and they do so without assistance, but at busy streets when they cannot hear or see the traffic, most consider the risk to be too great to cross alone. The range of risks involved for crossing anything from quiet driveways to busy highways is considerable, and clients will vary in how much risk they feel comfortable taking. For example, some deaf-blind people will cross residential, dead-end streets where there are never more than two or three cars passing each hour, but others would not willingly take that risk.

The O&M specialists' role is to help their deaf-blind clients understand what risk there is by describing the situation and helping them "observe" the traffic during different times of the day. This can be done by having the client place his/her hand on the hand of the instructor or a friend who points to the cars passing by, or by giving the client a signal whenever a car passes. The instructor needs to also explain how visible the client is to drivers and how the

drivers react to the client. After getting all the information, clients will decide whether or not they want to risk crossing there alone. If they do, they will increase their safety by warning any drivers who might potentially be passing (e.g., by moving their cane forward before stepping out).

If the client decides not to risk crossing there alone, the O&M specialist can help him or her come up with alternatives, such as getting assistance to cross; planning an alternative route; using paratransit or a car pool; and so on. If the street must be crossed to reach a bus stop, the crossing might be avoided by riding the bus to the end of the line and back.


If the client decides to get assistance, many of the same strategies for communicating with the public that were discussed earlier would be effective here. Some deaf-blind people rely on gestures to indicate they need help to cross, some use a card and/or their voice or recorded message to ask for assistance, and some get attention by using a whistle. If the person stands facing the street while trying to get assistance, people are more likely to realize he or she wants help to cross rather than for something else. For places where few pedestrians pass by, deaf-blind people have been very effective at getting assistance from store and business personnel and neighbors, sometimes calling them ahead of time (using an accessible TTY and relay service) to ask the helper to watch for them. Also, they have successfully gotten drivers to stop their car, get out, and guide them across streets by holding up a large sign where the drivers can see it, with large letters asking for help to CROSS STREET.

At intersections with traffic signals, deaf clients who can see the traffic and/or see the traffic signal or feel its vibrations (if a tactile traffic signal was installed) well enough to know when it's their turn to cross need to know how to avoid the traffic that turns into their path. If they are relying on their remaining vision, they need to know, for example, that when they start to cross with the parallel street on their right

Many deaf-blind people assume that the public understands that they are deaf and knows how to communicate with them.

they must first glance to the left to be sure no one is turning right on red. As they approach the middle of the street, they must look over their right shoulder to see if anyone is turning left from behind them on the parallel street and forward to see if anyone is turning right. It is important to be sure they understand this concept, because it is surprising how many visually impaired people, both deaf and hearing, don't understand these principles and will look toward the left when any traffic that could endanger them at that point would be coming from the right.

Conclusion

Teaching O&M to people who have both hearing and visual impairments can be challenging but very rewarding. The O&M specialist who accommodates to provide clear, comfortable communication and who is creative and flexible enough to adapt the O&M techniques as needed for the person who cannot hear can provide a very effective, successful O&M program for these clients. 

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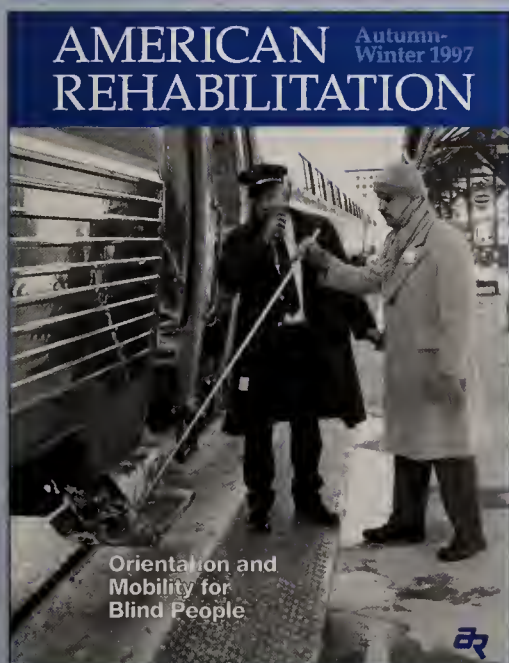
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Mobility Training for the Older Blind: A Common Sense Approach

L. James Witte

The biggest obstacle an older individual who is blind faces in developing independence in general and mobility in particular is not the learning of the necessary skills but the sparsity of rehabilitation services available to this population. This situation frustrates both the individual and the agency involved, as they struggle to meet a need with inadequate resources. Because of this problem, any discussion of mobility training for the older blind must first explore both the needs of this group and the barriers to meeting those needs, before discussing the techniques involved in providing that training.

People over 65 make up from 60 to 70 percent of the blind and severely visually impaired population. This age group is also the fastest growing group. This population needs and can benefit from sound rehabilitation training. Such programs for blind persons of any age are built on the premise that most tasks that need to be accomplished in any walk of life do not require vision. A blind person can participate fully in the community if he or she learns the appropriate alternative techniques of blindness. The validity of this approach has been demonstrated repeatedly as the number of successful blind people who have participated in these programs increases.

Advanced age alone does not negate an individual's ability to learn. In society at large, many senior citizens participate in elder hostels, pursue second careers, or become involved in volunteer work—all of which require the ability to learn. Like their sighted peers, older individuals who are blind can also learn and can benefit from the training of a good rehabilitation program, as evidenced by the competencies developed by those who have already received such training.

The need of the older blind for training in alternative techniques is not being met. The rehabilitation literature has discussed this problem over the past 30 years. However, no solution has been agreed upon. As a result, a large number of older blind people in many locales are simply not getting a "fair shake." Two major barriers preventing this are:

- the federal laws and regulations pertaining to rehabilitation, and

- the amelioration of the condition of the blind on one hand, and an artificial shortage of professional workers in some fields of rehabilitation on the other.

Federal Laws and Regulations

Historically, older blind persons have experienced difficulty in securing training services when such individuals are not pursuing employment. Rehabilitation agencies serving blind people typically administer rehabilitation programs that focus on employment. Some separate state agencies for the blind have offered older blind persons a wide range of services, such as a library, access to aids and devices useful to the blind, radio-reading programs, and perhaps some effort at employment through a home industries program. But these services, valuable as they are, have generally been thought of as more ameliorative than rehabilitative. In addition, there has often been some "bootlegging" of home teaching services, including mobility training, to persons like the older blind whose vocational goal was probably ephemeral. Even then, such home teaching in many states did not include mobility training because of the policy of some agencies to hire only mobility teachers with master's degrees in orientation and mobility (O&M). Because the number of instructors possessing such credentials was small, these states were unable to hire enough mobility instructors to meet the needs of blind people, including those who were older.

In 1978, the Federal Government made some effort to serve the older blind population. Federal funding for what came to be known as "Centers for Independent Living" enables some agencies serving the blind to formalize separate

programs for blind people, including the elderly, who are not pursuing vocational goals. Independent living centers initiated by state agencies for the blind take different forms. In some places, individuals come to a central location to receive instruction in a wide range of blindness techniques. In others, the centers send out itinerant teachers to work with blind persons in their communities. In still other instances, agencies contract with others for the provision of rehabilitation services to the older blind. In any case, the development and continuing existence of these centers represents a national recognition of the needs of older blind people and a commitment to meet those needs.

Not all of these centers can offer mobility training, however. Those programs tied to the requirement that only O&M practitioners with a master's degree can provide such training find themselves limited by a shortage of qualified staff. Consequently, the elderly blind get the "leftovers" of such training—if they are lucky enough to get anything at all. Agencies that did not require graduate level training in mobility of its staff did not experience this problem.

There was an additional and unexpected benefit to locating an independent living program within a separate state agency for the blind. Common public attitudes and misconceptions about blindness, when adopted by newly blinded people themselves, can be devastating. Many such persons, at any age, have a tendency to "sell themselves short." Training in the more open-ended approach of independent living can help such persons overcome their lack of self-confidence. Many of these students, including the older blind, have eventually found themselves wanting to expand their goals beyond independent living and were able to easily transfer to the vocational rehabilitation program available in the same agency.

Both the initial concept of independent living centers and the categorical funding of rehabilitation training for the older blind within separate state agencies for the blind were largely beneficial. Unfortunately, changes detri-

mental to the provision of these services came with the passage of the 1992 Amendments to the Rehabilitation Act. Prior to 1993, all three funding streams in Title VII could provide categorical funding for blind individuals. The State Independent Living Services formula grant (formerly Part A, now Part B) provides funds directly to all state agencies, general and blind. These funds continue as before and can support a broad series of innovative programs, including programs either directly operated by state agencies serving blind people or through a subgrant or contract from these agencies. As before, states determine the priority for expenditure of these funds. A large change occurred in the Centers for Independent Living Program (formerly Part B, now Part C). Before 1993, centers were able to serve single disability groups such as the blind; however, after 1993 centers must be nonprofit organizations that serve individuals with all significant disabilities. The Independent Living Service for Older Individuals who are Blind Program (formerly Part C, now Chapter 2) continues as before to provide services to older blind people. The Chapter 2 program is the major source of federal funds available to provide independent living services to older blind people. There are now grants in every state and territory except the Commonwealth of Northern Marianas.

This change has had a drastic effect on the rehabilitation services, particularly mobility services, that have been provided to older blind people. With the shortage of qualified mobility instructors—even those without advanced degrees in O&M—most private, cross-disability independent living centers could not find a sufficient number of qualified staff to serve their consumers.

The problems of blindness are complex, requiring those who work with blind people to have comprehensive knowledge and understanding unique to the field. Any teacher of the blind must approach the task from two directions: teach the skills—including mobility—necessary to deal with the problems resulting from the physical loss of eyesight and, more important, deal with

the public misconceptions about blindness that prevent blind persons from developing the self-confidence necessary to live independently. Training in the alternative techniques of blindness and achieving this attitudinal shift takes time, particularly for older blind individuals. Given a shortage of funds and the agency's need to meet "production goals," blind people, especially those who are older, are less likely than people with other disabilities to receive adequate services under this system. It is ironic that blindness, which is generally thought to be among the worst of all disabilities, is expected, under this system, to be dealt with like all other disabilities. It is even more ironic that, in the past, this argument had been successfully used to maintain separate programs for blind people.

The second major barrier to the delivery of services to older blind individuals—an artificial shortage of trained rehabilitation specialists, particularly mobility instructors—has already been alluded to. There would not be much point in discussing curriculum and methodology in teaching mobility to older blind persons if there are no teachers available. The issue of who is qualified to teach mobility has been debated since World War II, when the long white cane came into use. Soon after the efficacy of the Veterans Administration (VA) mobility program was recognized and state and private agencies began to emulate it during the 1950's, a strong movement arose to systematize this field and to give it specialized professional status by requiring master's degrees in orientation and mobility.

This movement occurred not without some strong opposition. Discussions have been ongoing about what kind of certification should be required of mobility teachers, about whether blind persons can or should be allowed to teach mobility, about such methodology

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as one-on-one instruction, and about whether paraprofessionals should be allowed to assist in the instruction process. There has also been a growing awareness that the emphasis being placed on graduate level education with its resultant certification and methodology has resulted in a severe shortage of mobility training for many blind people, especially the older blind.

The National Council of State Agencies for the Blind (NCSAB) has been extensively involved in trying to resolve what appears to be a standoff in this controversy. In 1983, 41 directors of state agencies serving the blind participated in an NCSAB survey dealing with this issue. There was some disagreement on the question of whether both rehabilitation and O&M teachers should receive training on the graduate level. Thirty-one directors thought rehabilitation teachers could also teach mobility, while nine disagreed. Ten respondents required their mobility teachers to have master's degrees in orientation and mobility, but 25 did not.

Since the early 1980's, a debate on this issue has taken place continuously between the NCSAB and the Association for the Education and Rehabilitation of the Blind and Visually Impaired (AER), which strongly maintains that graduate level training and certification are necessary. The NCSAB, on the other hand, suggests alternative approaches, such as reducing the requirements for graduate level training and providing short-term training for rehabilitation teachers of the blind which would enable them to add the teaching of mobility to their repertoires. The NCSAB approach has been proven to be successful in those agencies that have developed comprehensive mobility training programs that do not require graduate level preparation, that recognize that blind persons can teach mobility, and that, consequently, allow for their rehabilitation teachers, independent living teachers, and vocational rehabilitation counselors to provide mobility training as just one of a variety of skills available. This approach has meant that older blind people, whether in rural or urban areas or in residential

centers, are receiving from these agencies mobility training on the same basis as blind people of any other age group. With the success of this approach and the increasing needs of a growing older blind population, the allegiance to requirements that are unnecessary must be reconsidered.

Common sense and creativity are the keys to teaching mobility to older individuals who are blind. The instructor must first be aware of two caveats, though. When teaching this skill to anyone who is blind, the teacher is often tempted to categorize that person and then to predetermine the type of training that will be offered based on such characteristics as age, physical condition, and mental capacity. In the past, specialized approaches have been developed for groups like children, the elderly, the diabetic, the traumatic brain injured, and the hearing impaired. But the experienced practitioner soon comes to understand that each person, both regardless and because of his unique combination of characteristics, does not fit into any of these specialized categories. There are blind persons in their seventies who are as independently mobile as anyone can be, and there are young persons who have great problems in mobility because of loss of balance, hearing, or tactile deficiencies. Therefore, the instructor must not look to specialized programs for the solutions to any given individual's problems in developing independent mobility skills but should be observant and creative in dealing with the factors that will impact on how well a particular individual may develop those skills. The incidence of additional disabling conditions within the older blind population is generally greater than among other groups, but this factor should only stimulate the teacher's ingenuity more and not cause that teacher to look for a special mobility program for this group.

The second caveat for the teacher to bear in mind is that much of the skill of independent mobility for blind persons of any age is self-taught. If the student is to teach him-/herself, the teacher must then serve as an observer, a sug-

gester, and a motivator, giving the student the necessary leeway to explore and experiment on his or her own so that the student can reach the highest skill level possible. A student who is not allowed to do so will be tempted to restrict him-/herself unnecessarily when no longer under the watchful eye of his/her instructor.

This discussion is focused on the long cane method of mobility instruction. Both the use of the guide dog and the use of electronic devices are very specialized areas that would require separate treatment. Mobility instructors must familiarize themselves, however, with these areas so that they can provide their students with meaningful information about them. This is particularly true of electronic mobility aids, an area where there are likely to be more technological advances. As such developments occur, more blind people will become interested in receiving training with such devices and mobility instructors must be in a position to provide or to help them find this training.

Many types of long canes are available. The teacher needs to point out the advantages and disadvantages of each, mindful that the student may try out several before finding a favorite. The teacher must keep in mind, though, that a white cane may be the last thing a newly blinded person of any age wants. To most people the white cane symbolizes all the unfortunate misconceptions many hold about blindness, which is why many blind persons try to hide the cane or get along without it as long as possible. This situation can be especially true for a newly blinded older person, who may be resistant to learning new skills and whose negative notions about blindness are deep seated. As encouragement, the teacher may have to point out that the cane is not just a useful tool but also a positive symbol of the fact that a blind person can be independent and mobile in an efficient and safe manner. If the teacher helps the student adjust to having a cane, that student will be more likely to use it properly and with self-confidence.


As the older person who is blind adjusts to owning and using a cane, the mobility teacher may find it necessary to make more modifications for his training than for a younger blind person. Some older blind individuals live at home, while others are residents of nursing homes. Some may have no orthopedic problems, while others may be using a walker, a support cane, or a wheelchair. Various approaches have been developed for dealing with these situations. Some older blind people, for example, use a lightweight long cane in conjunction with crutches or walkers or support canes. Some wheelchair users have found electronic mobility devices to be helpful.

Common sense and creativity are also helpful in choosing an optimal location for mobility training for the older blind. The mobility teacher usually works with an individual in his place of residence. Some agencies, however, have successfully modified this

approach. One such modification is to have several older blind individuals attend a minitraining center each day for a week or two. Located in a central geographical area and staffed by one or two rehabilitation teachers, this approach makes a maximum use of staff, allows for the teaching of several skills, including mobility, and provides the opportunity for blind persons to share experiences and notions about blindness with each other. A second modification uses a residential training center for the blind to allow a larger group of older blind persons to live for a time in an atmosphere most conducive to dealing with the problems of blindness and to take advantage of all of the available instructional facilities. A third approach involves using peers as resources to help newly blinded older persons learn the skills and self-confidence necessary for living independently.

In working with older blind individuals, the mobility instructor is likely

to encounter many problems that have already been solved by others. Discussing those problems with other mobility teachers can be helpful. Valuable information can also be found in many publications. *The Journal of Visual Impairment and Blindness* has published many articles on mobility issues. The American Foundation for the Blind has also published numbers of books and articles written by practitioners in the field. Organizations of the blind, including the National Federation of the Blind and the American Council of the Blind, can also be very useful resources.

The best advice, though, that can be given to a mobility instructor who works with older persons who are blind is this: If you know and understand the skill and have the ability to teach—do it. Too many older blind persons are still being denied the opportunity to lead full lives because they do not have the opportunity to learn the necessary skills and develop self-confidence. 

Library of Congress to Explore Educational Reading Services for Print Handicapped Students

Provision of educational reading services to people with print disabilities, including elementary, secondary, and college-level students, will be the focus of a major study announced by the National Library Service for the Blind and Physically Handicapped (NLS), Library of Congress.

The study, estimated to take 1 year to complete, will examine the current constellation of agencies and individuals who provide these students with materials in alternative formats. It will search for mechanisms through which the skills of NLS and its network of cooperating libraries might be utilized to serve eligible students.

According to the October 27, 1997, issue of *Newsweek* magazine, "In an astonishing estimate, some researchers now say that as many as 20 percent of schoolchildren may have a neurological deficit, ranging from mild to severe, that makes it hard for them to read and write." Using the 20 percent estimate, more than 13 million of the projected 67 million students in the United States could be eligible for Library of Congress services.

In announcing this study of both the informational and educational reading

needs of this segment of the population, Frank Kurt Cylke, director of NLS, said, "The largest single organization now serving this group provides materials to only about 39,000 individuals. While other groups and many individuals also provide materials to thousands more, there may be a need for central coordination of their efforts.

"NLS with its cooperative network of 140 lending libraries throughout the United States has matured in its 66 years of existence to a level of sophistication where together we believe we can extend our national program to cover educational needs of the eligible population," Cylke said. "In addition, the Library of Congress is currently embarked on the development of a national digital talking-book technical standard through the National Information Standards Organization. We will ensure that this standard will meet future scholastic and academic needs as well."

The NLS network functions as the largest and frequently sole source of public library materials and services for the population who cannot readily use the

print materials of local libraries. The NLS network annually circulates more than 23 million books and magazines in Braille and recorded formats to a readership in excess of 776,000 eligible U.S. adults and children. The great majority of the network of cooperating libraries operate within state library systems that are committed to serving the informational, educational, and recreational needs of individual readers.

"NLS embraces the vision 'That All May Read' and participates in the Library of Congress's commitment to lifelong reading. As NLS steps into the next millennium, it is our obligation to review and improve services to all the populations we serve," Cylke said.

Suggestions and comments are welcome. They may be addressed to the survey project coordinator, Michael M. Moodie, Research and Development Officer, NLS, Library of Congress, Washington, DC 20542. Mr. Moodie may also be reached by telephone at (202) 707-5108 or by facsimile at (202) 707-0712. His E-mail address is: mmoo@loc.gov

The Cognitive Paradigm for Teaching Cane Travel

This article presents the key elements of a paradigm for teaching cane travel that is grounded in cognitive learning theory. The "cognitive paradigm" for teaching cane travel applies developments in learning theory that shift the focus away from what the instructor teaches. Instead, attention is directed to what best facilitates student learning.

Richard Mettler

correct performance. Also, there is sincere commitment to the belief that visual monitoring by the instructor is the only reliable way to ensure student safety during training. These practices reveal limited expectations of blind people. This bias toward the visual model of the world is understandable, given the dominance of visual assumptions in the public mind. It can require concerted effort to suspend those assumptions sufficiently to understand adequately how a nonvisual model of the world might be constructed. I acknowledge that in stating the case for the cognitive paradigm I am describing the teaching practices of O&M as an outsider looking into the profession. Whether this characterization of the practices of O&M is accurate and fair I leave to the reader to decide. The purpose of this article is to establish that *if* my comments on O&M are generally accurate, then the alternative cognitive paradigm to teaching cane travel commands serious consideration.

Each instructional model claims skillful, independent blind cane travel as its desired teaching outcome. The traditional approach to skill training generally—and as exemplified in traditional O&M teaching in particular—stresses the use of guided teaching methods, including a heavy reliance on "extrinsic" (instructor-generated) feedback (also known as "enhanced" or "augmented" feedback) to assess and direct student performance in practice. The cognitive paradigm to teaching cane travel stresses discovery teaching methods and "intrinsic" (student-generated) feedback (also known as "inherent" or "response-produced" feed-

back) to govern student performance and to access knowledge of results (KR). It is agreed that KR is necessary for learning to occur. In the cognitive paradigm, it is maintained that student-derived KR is preferable to instructor-derived KR for the purposes of skillful and independent cane travel. These differences in teaching practices reflect some fundamental conceptual differences of opinion about the nature of the experience of blindness and what constitutes competent and effective blind cane travel. These differences too must be surfaced and understood adequately before meaningful comparative testing can proceed. It is argued here that the cognitive paradigm better promotes important perceptual, cognitive, and motor skills that are necessary for effective travel skill acquisition, retention, and transfer, as well as problem solving and decision making. The cognitive paradigm applies research developments in psychomotor skill learning (e.g., Bjork, 1994; Schmidt & Bjork, 1992; Schmidt, 1991a; and Schmidt, 1991b) to the teaching and learning of cane travel. Application of the research developments of the kind represented proceeds initially by simply defining cane travel as a psychomotor skill. With this move, the cognitive paradigm inherits a wealth of research evidence in its support.

With the details of the cognitive paradigm explained, the next step is to test with controlled research the cognitive paradigm to teaching cane travel against the traditional model of O&M teaching. However the particulars of such a research project might take shape, it would be critical that it be designed with the following explicitly in mind: Any such research project would not just be testing two teaching approaches against one

This article further develops and refines the contrast between what is termed the cognitive paradigm to teaching cane travel and the teaching model that appears to strongly influence, if not dominate, the practices of the profession of orientation and mobility (O&M), which is referred to here as the visual monitoring paradigm. This contrast has been developed in previous work (e.g., Mettler, 1995; Mettler, 1994; and Nyman & Mettler, 1993). In the visual monitoring paradigm, the instructor assumes a high profile, as instructor involvement and control remains considerable throughout the process. Visually grounded instructor observations are relied upon as the most authoritative means to inform the student about the level of his or her performance and to reinforce

another in isolation, but would be comparing two distinct instructional paradigms against each other.

Discovery vs. Guided Teaching

Practice conditions should generate subjective experiences that accurately demonstrate to the student the true nature of the task to be learned and the student's current level of achievement in managing the demands of his or her environment. Traditional training approaches often mislead the student on both (cf. Bjork, 1994). Traditionally, relatively permanent learning effects have been inferred from the conventional approach, while only temporary performance effects have been observed in practice. Learning, retention, and transfer are treated as separate phenomena. In the cognitive paradigm this is effectively reversed. Performance in practice and learning are always treated as potentially separate phenomena, while learning is defined and measured by retention and transfer. Even when performance in practice is treated as a probable rough indicator of the amount learned, this is done only after careful examination of the conditions of the practice environment. An explicit goal in the cognitive paradigm is for the task practiced to be as close as possible—if not identical—to the task awaiting in the post training environment. The process of preparing travel students for this task identity begins during the first travel lesson and is viewed as a brief orientation phase to the substantive learning phase of training. During the first travel lesson, the student begins to process intrinsic feedback for self-monitoring and decision making. This shift in the locus of control from instructor to student is progressively and rapidly expanded and refined until the student is effectively demonstrating independent cane travel. Discovery learning requires a significant investment of preparation time, and this preparation constitutes the structured element of the teaching approach. Guidance by the instructor gradually diminishes until the student has sufficient grasp of fundamental

skills and knowledge, at which point the teaching strategy changes. Timing here is important. While supportive of guidance as a preparatory training tool, Schmidt (1991a) cautions, "Guidance procedures can easily be overdone, however, and should therefore be removed as quickly as possible, probably at about the point that the learner is just capable of performing the task independently" (pp. 182–183). Practice manipulations that focus on rapid improvement in performance through guided teaching methods often do so at the expense of the actual skills eventually needed by the student to be a truly independent traveler.

In heavily guided teaching the instructor becomes too helpful in ensuring good student performance in practice. Independent attempts at demonstrating the skill become attempts at tasks with which the student is not sufficiently familiar, for they are not the same as those practiced. Schmidt (1991b) states that excessive extrinsic feedback can *become part of the task* just as the sounds of an automobile become part of the task of driving—part of the information used while driving. Schmidt (1991a) also states "the learner who does not receive guidance, forced to struggle somewhat more during practice, does not perform as well during the acquisition phase. But this person *learns* the capability to perform effectively without guidance and thus outperforms guided learners on a retention test" (p. 182).

Guided learning often involves processing what the instructor says as the primary task. Other information processing becomes a secondary task which can require more attention than is available. During independent performance, processing the experience of the action is the sole task to which full attention can be directed.

Guidance would be a useful training tool if all demand aspects of cane travel could be handled by parallel, automatic information processing. But too much of effective cane travel calls for serial, controlled information processing, with fixed attention capacity. When the student is attending to the instructor's directions or extrinsic feedback,

too much attention is required in processing this verbal information for the student to process other kinds of information. Since the instructor's comments are more compelling, this other information can escape the student. Schmidt (1991a) thinks of attention in this regard as "related to the limitations in doing two things at the same time. . . . [so] if two tasks interfere with each other, then they both demand some access to the limited capacity to process information; that is, they both require attention" (p. 31). When the instructor is doing the work in directing and assessing student performance, the student lacks both the attention resource and motivation to process intrinsic, response-produced feedback. But the student must be able to process this information independently in the instructor's absence. Schmidt (1991a) states "during practice where guidance is present, the learner relies too strongly on its powerful performance enhancing properties, which actually changes the task in several ways. Physical guidance modifies the feel of the task. When the instructor tells the learner what to do, decision making changes" (P. 181).

Once the equivalence between performance in practice and the learning that can be claimed is broken, the way is open conceptually to manipulate practice conditions to promote better learning. In traditional training the emphasis is generally placed on what the instructor knows and how that knowledge is communicated to the student. In the cognitive paradigm the emphasis is placed on how the student learns and the experiences which best promote this learning. Drawing from the research program of what is called *cognitive science*, the cognitive paradigm proceeds from the belief that knowledge is *constructed* through the organization of

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subjective experiences, and not simply acquired. Students come to the training environment with an existing knowledge base for new experiences to be mapped on to for encoding and subsequent retrieval. In traditional training, this encoding still occurs but often the information encoded is not that which is most relevant to independent performance. Schmidt (1991a) defines *error detection* as, "The learned capability to detect one's own errors through analyzing response-produced feedback" (p. 284). He states "almost all tasks are richly associated with response-produced feedback that potentially informs the learner about success. Learning error detection means learning sensitivity to the particular patterns of response-produced feedback related to the performance outcome" (1991a, p. 217). In cane travel, this sensitivity is facilitated by the instructor requiring the student to comment on aspects of his or her performance. Accuracy of subjective estimations about performance prepares the student to detect errors independently, which provides opportunity for independent error correction. Schmidt (1991a) states, "Forcing the learner to report on such movement aspects means the learner must devote attention and effortful processing to the feedback produced by the response. This forces greater familiarity with the particular feedback, leading to the capability to detect errors" (p. 217).

However, Schmidt (1991a) cautions instructors, "Be careful. . . that your instructions do not force attention to response-produced feedback during the movement. The performer would then be attending to sources of feedback other than the ones critical for performance. However, after the movement is completed, ask the learner to describe some feature of the movement to draw attention to the sensations the movement has just produced" (p. 217).

I would add that the instructor *should not speak at all* during this time when the student is engaged in this information processing. As with most motor skills, the experience of cane travel is rich in intrinsic feedback information to be deciphered. The be-

ginning travel student can be confused by the amount and variety of intrinsic feedback once attention is drawn to it. Any conversation by the instructor at these times can further detract from the clarity of the information.

Practice Conditions

Optimal practice manipulations introduce a variety of difficulties and challenges for the student that traditionally have not been present in training programs. Bjork (1994) calls these practice manipulations "desirable difficulties," and submits, "it seems safe to say that in responding to the difficulties and challenges induced by such manipulations the learner is forced into more elaborate encoding processes and more substantial and varied retrieval processes. . . . [Such] manipulations are likely to induce more 'transfer appropriate processing' . . . that is, processing that will transfer to the post training environment" (p. 192).

These manipulations make skill acquisition in practice significantly more taxing for the student as they create many more opportunities for students to experience mistakes in performance. While this degrades performance in acquisition, the student *is learning* the posttraining criterion goal through organizing the subjective experiences associated with identifying, understanding, and recovering from mistakes as they occur. Traditional training programs attempt to minimize or prevent student error in favor of optimizing performance. However, as Bjork (1994) states, "Manipulations such as blocking practice by subtask, providing continuous feedback during training, and fixing the conditions of practice act like crutches that artificially support performance during training. When those crutches are absent in the posttraining environment, performance collapses. The learner, however, will typically lack the perspective and experience to realize that he or she has not yet achieved the level of learning demanded by the posttraining environment" (p. 196).

The practice manipulations that minimize the occasion for mistakes in prac-

tice only defer those mistakes to the posttraining environment, where the cane traveler does not have the learning environment in which to explore and understand these mistakes.

Among optimal practice manipulations are the following:

- Fading the use of extrinsic feedback in favor of the student concentrating on intrinsic feedback for obtaining knowledge of results;
- Providing contextual interference (e.g., by practicing in varied and challenging environments);
- Distributing practice trials, as opposed to massing practice;
- Incorporating frequent tests in practice requiring the student to recall what has already been learned (i.e., frequent retrieval practice); and
- Varying practice scheduling so the student is not practicing the same task in long repetitions.

Bjork (1994) claims, "It has now been demonstrated in a variety of ways, and with a variety of motor, verbal, and problem-solving tasks, that introducing variation and/or unpredictability in the training environment causes difficulty for the learner but enhances long-term performance—particularly the ability to transfer training to novel but related task environments" (p. 189).

The fact that these practice manipulations yield comparable research results for both adults and children—and with verbal-cognitive as well as psychomotor tasks—suggests that we are dealing with phenomena of considerable importance to human learning generally (see also Schmidt & Bjork, 1992, and Winstein & Schmidt, 1990).

Bjork (1994) states "the research picture is unambiguous: A variety of manipulations that impede performance during training facilitate performance on the long term" (p. 192) and suggests reasons for why they are not being incorporated into traditional training programs:

1. Instructors are underexposed to relevant research findings.
2. "More important than any underexposure to relevant research findings, however, is the fact that the typical trainer is overexposed, so to speak, to the day-to-day performance and eval-

uative reactions of his or her trainees. A trainer, in effect, is vulnerable to a type of operant conditioning, where the reinforcing events are improvements in the performance and/or happiness of trainees" (Bjork, 1994, p. 193).

3. Contributing to the above, instructors are often evaluated on the basis of student performance gains in practice and student satisfaction with the training experience. "Rapid progress in the form of improved performance is reassuring to the learner, even though little learning may be taking place, whereas struggling and making errors are distressing, even though substantial learning may be taking place. Such a misreading of one's progress, . . . can lead trainees to prefer less effective training over more effective training" (Bjork, 1994, p. 194).

4. Many instructors never see student posttraining performance, and so are not confronted with the reality of sub-practice performance in real-world settings: "a trainee's later successes and failures tend to occur in settings that are far removed from the original training environment, and from the trainer" (Bjork, 1994, p. 193).

5. "It is also rarely the case that systematic measurements of posttraining on-the-job performance are even collected, let alone provided to a trainer as a guide to what manipulations do and do not achieve the posttraining goals of training" (Bjork, 1994, p. 193).

6. "And, finally, where refresher or retraining programs exist, they are typically the concern of individuals other than those responsible for the original training" (Bjork, 1994, p. 193).

The cognitive paradigm is in sharp contrast to traditional teaching, where practice conditions artificially support and facilitate student performance and, thereby, systematically mislead both student and instructor as to the student's level of learning and ability. Excessive use of extrinsic feedback is primary among the nonoptimal practice manipulations that are representative of guided teaching methods. Schmidt and Bjork (1992) note, "It has generally been understood that any variation of feedback in practice that makes the infor-

mation more immediate, more accurate, more frequent, or more useful for modifying behavior will contribute to learning, as measured during the acquisition phase" (p. 212). But excessive feedback brings with it a number of detrimental effects:

- This feedback tends to create a performance dependency on the instructor and the instructional setting.

- Extrinsic feedback can interfere with important internal student information processing, such as error detection.

- Extrinsic feedback motivates too many trial-to-trial adjustments, which can impede consistency in performance.

- This feedback tends to make performance "too easy."

Bjork (1994) argues, "Training conditions that prevent certain mistakes from happening (and give trainees a false optimism about their level of comprehension and competence) can defer those mistakes to a posttraining setting where they really matter. . . . Stated most strongly, when embarked on any substantial learning enterprise we should probably find the absence, not the presence, of errors, mistakes, and difficulties, to be distressing—a sign that we are not exposing ourselves to the kinds of conditions that most facilitate our learning, and our self-assessment of that learning" (p. 201).

This calls for some fundamental rethinking as to what practice conditions should be, the benefits that they promise, and the costs involved in avoiding them. Bjork (1994) states, "For people to be receptive to the types of manipulations of training suggested . . . institutional and individual attitudes toward the meaning of errors and mistakes must change. People learn by making and correcting mistakes" (p. 201).

Self-Efficacy

A common traditionalist objection to learning through the experience of error is that if the instructor orchestrates occasions for student mistakes, especially early in training, by withholding extrinsic feedback and other forms of guidance, the student will then lose

confidence in the travel system being taught—thinking of it as unreliable and fearsome. The objection continues that some students come to the training environment already so lacking in self-confidence that perceived failure will only further diminish self-esteem and motivation. This is a valid objection as far as it goes and deserves some comment, for it turns on a core belief in the cognitive paradigm: *Learning begins with self-perceived efficacy*. In the cognitive paradigm the detrimental effects of the experience of error are avoided by attacking the sense of helplessness that the experience of error tends to promote if appropriate intervention and context setting are not taken. In the cognitive paradigm the student understands from the outset that he or she is the author of the travel experience, mistakes and all. Training strategies that concentrate on preventing student error do so by incorporating a substantial amount of guided teaching. This unavoidably places the locus of control within the instructor and can inhibit a student's perceived "self-efficacy" (Bandura, 1982, & Bandura, Reese, & Adams, 1982), a key force recognized in cognitive learning theory.

The instructor who assumes the responsibility for monitoring student safety and who continues to be the authority regarding student performance promotes student dependency, which, in turn, is an obstacle to self-assured achievement. The student in this case fails to develop a sense of self-efficacy: self-referent belief in one's ability to cope and succeed. This directly influences one's expectations for oneself. Bandura (1982) states, "Self-percepts of efficacy influence thought patterns, actions, and emotional arousal. . . . [The] higher the level of induced self-efficacy, the higher the performance accomplishments and the lower the emotional arousal" (p. 122).

Fear and self-doubt must be overcome before the student can develop the self-assurance necessary for self-regulation. The dynamic at play here is that of learning and performance reaching their ceiling at the current level of self-confidence: the imagined ability to

use the knowledge and skills being acquired. To increase learning and improve performance, self-confidence must increase. While Bandura sees this phenomenon at work widely in human conduct, blind people constitute a group that is particularly vulnerable to self-doubt. It is no exaggeration to claim that the greater society does not expect much from blind people. When blind people internalize low expectations, inability is perpetuated. Bandura (1982) argues, "People who are skeptical of their ability to exercise adequate control over their actions tend to undermine their efforts in situations that tax capabilities" (p. 129). This self-doubt naturally detracts from one's interest in an activity and can obstruct one's willingness to put forth effort.


Low self-efficacy creates fear of tasks that are unfamiliar or potentially aversive, such as cane travel. It is critical for the student to confront and overcome this anxiety quickly, by understanding the global skill of cane travel as composed of attainable subgoals that prepare the way for the attainment of more ambitious future goals. Bandura (1982) states, "Subgoal attainments provide clear markers of progress along the way to verify a growing sense of self-efficacy" (p. 134). It is common for students to overestimate the demands of cane travel and to underestimate their ability to meet those demands. Because of this, early experience with independent successes, however modest, is necessary to negate the sometimes paralyzing effects of fear arousal in favor of a confident understanding that the skills of cane travel are within reach. Bandura (1982) states, "From the social learning perspective, it is mainly perceived inefficacy in coping with potentially aversive events that makes them fearsome. To the extent that one can prevent, terminate, or lessen the severity of aversive events, there is little reason to fear them. Hence, experiences that increase coping efficacy can diminish fear arousal and increase commerce with what was previously dreaded and avoided" (p. 136).

Continued and substantial external reinforcement often fails to translate into an internal, personal sense of com-

petence. Self-doubt can be maintained in the face of extravagant instructor approval. Bandura (1982) discusses *proximal self-motivation* in this regard: "Contingent incentives are not necessarily the best vehicle for enlisting the type of sustained involvement in activities that builds interest and self-efficacy where they are lacking. In social learning theory an important cognitively based source of motivation operates through the intervening processes of goal setting and self-evaluative reactions This form of self-motivation, which involves internal comparison processes, requires personal standards against which to evaluate performance. By making self-satisfaction conditional on a certain level of performance mastery, persons create self-incentives for their efforts" (p. 134).

Self-motivation, also known as *mastery orientation*, is another key force in cognitive learning theory. Self-motivation, as opposed to motivation derived from external reinforcement, it is argued, produces better learners.

Students of instructors who take on too much of the work in student learning and performance have their self-efficacy undermined by relinquishing personal control in their actions. Bandura (1982) calls this *proxy control*, explaining, "People are not averse to relinquishing control over events that affect their lives in order to free themselves of the performance demands and hazards that the exercise of control entails. Rather than seeking personal control, they seek their security in proxy control—wherein they can exert some influence over those who wield influence and power. Part of the price of proxy control is restriction of one's own efficacy and a vulnerable security that rests on the competencies and favors of others" (p. 142).

Proxy control can result in learned helplessness. Until people experience independent success at a task, they lack personal criteria for perceived efficacy, which impairs achievement motivation. Without perceived efficacy, dependence on proxy control is appealing. But proxy control fails to provide opportunities for success that promote self-efficacy. Hence, the circle is complete. 

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Teaching Cane Travel: *A Blind Professional's Perspective*

Arlene Hill

The notion that blind instructors are at a disadvantage compared to sighted ones when teaching orientation and mobility (O&M) to blind people is one of the greatest misunderstandings in the field of blindness. There are, admittedly, differences in the two approaches, but these differences—philosophical as well as practical—seem to be based on different techniques employed by sighted versus blind instructors.

Until I learned to use a cane successfully, I may have taken the opposing view. I grew up in Knoxville, Iowa. I attended both the Iowa Braille and Sight Saving School in Vinton and Knoxville High School, the local public high school in my hometown. From childhood through my high school years I never had a cane in my hand. I believed that canes were for blind persons who were less capable than I. My attitudes were no better than most sighted people, as I then reflected the common belief that blind people are really not very capable when it comes to independent mobility. Although well-trained blind persons overcome this myth, it nevertheless persists among most sighted people who have not undergone extensive sleepshade training.

Sleepshade training is a technique used by many instructors and university training programs. A black mask or covering is placed over the eyes of the student. Because the student's vision is thus completely obstructed, he/she is able to thoroughly learn the alternative techniques for travelling safely and independently. If a person has progressive eye disease, training with

sleepshades requires him/her to prepare more effectively for the future, when his/her sight will be completely lost: the student must rely completely on the other four senses, rather than depend solely on limited vision. When a person is legally blind the natural tendency is to rely upon his/her minimal vision, even though a blind person with 10 percent or less vision is unable to complete tasks in the same visual manner as a fully sighted person. Based on my observations of students training in a variety of settings, using sleepshades seems to be the best way one can learn to trust alternative skills enough to use them and to become an independent cane traveller.

In my view, the major differences between blind instructors and sighted instructors are those of philosophy. . . .

After my high school graduation, I became a student at the Iowa Commission for the Blind in Des Moines, where I was introduced to the long white cane, long enough to come up to my chin. I was taught how to use this cane by a sighted instructor who had undergone extensive sleepshade training. It was immediately obvious to me that this cane was not just a symbol of blindness but was, in fact, a tool that

could be used to achieve true freedom. I have been a user of the long white cane for more than 30 years; and, as time has passed, the length of my cane has increased to the point that it is now as tall as I am. Some may find this fact curious; however, as one increases in both skill and confidence, one's walking pace naturally increases. Thus, one needs more stopping distance in which to react to potential obstacles, and the increased length affords that distance.

After attending the Iowa Commission for the Blind, my training was in the field of special education, with emphasis on teaching mentally disabled persons. I taught blind, mentally disabled individuals in a state hospital school for a number of years. I have been teaching cane travel for the past 12 years—3 years at Blind Industries and Services of Maryland in Baltimore and 9 at the Louisiana Center for the Blind in Ruston, where I am currently employed.

In my view, the *major* differences between blind instructors and sighted instructors are those of philosophy, and these differences give rise to the differing techniques used by blind instructors and by sighted instructors and cause some of the problems encountered by blind instructors.

Let us begin with what we call ourselves: cane-travel instructors, as opposed to university trained (AER certified) orientation and mobility specialists (O&M). In my opinion, cane-travel instructors are teachers who believe that they are teaching *already mobile* persons

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to travel independently by using the long white cane. I teach other blind people how to use the cane properly to locate obstacles and to detect other environmental cues. The technique is straightforward and simple and is one of the easiest tasks for most students to learn. However, developing problem solving skills and building self-confidence seems to be most difficult for students to accomplish. O&M specialists frequently spend a great deal of time teaching pre-cane techniques, sighted guide techniques, and protective methods. In contrast, most blind instructors teach through a "discovery" method of learning, which is designed to challenge students to problem solve. Blind instructors also serve as excellent role models, and because they use canes on a daily basis, blind instructors can share personal experiences with their students.

As a blind traveler and a blind instructor, I believe there are two important keys to being a good independent cane traveler—self-confidence and problem-solving skills—which, interestingly, are also important for persons learning to drive an automobile. Most teenagers cannot wait to drive, but when they sit behind the wheel for the first time it can be frightening. The same is true with a blind traveler: the first time he or she goes out on the street with a cane it is very frightening, because it, too, is unfamiliar territory requiring the use of undeveloped skills. The sound of traffic and the thought of potential harm can be overwhelming to many blind travelers, just as being behind the wheel of a fast moving vehicle is to many young drivers. In both cases, they return from their first trip and all is well—or at least it was not quite as bad as they thought it would be. Each subsequent trip becomes less frightening. As time passes, the drivers, as well as the blind travelers, build confidence until they truly believe in themselves.

Most people, blind and sighted alike, tend to do and become what others expect of them. If their instructor has high expectations for them and they, consequently, have high expectations for

themselves, they learn they can travel everywhere, mostly unassisted.

A good blind traveler believes in his or her ability to negotiate obstacles and expects to take on travel challenges throughout each day. Most sighted people, unless extensively trained under sleepshades, do not believe that a blind person can traverse the many unfamiliar hazards that he or she might en-

Most people, blind and sighted alike, tend to do and become what others expect of them.

counter daily. Yet, since a blind instructor is used to facing these challenges, he or she will expect and encourage students to do likewise.

The next key is problem solving skills, important for drivers and blind cane travelers. Can the person learn to use his/her entire environment to stay oriented or, if confused, to become re-oriented? We teach drivers to always be watching, with their eyes constantly moving. The good driver will be looking for landmarks, signs, traffic patterns, and traffic cues. We also teach blind persons to use all their senses and their minds to process information from everything around them for the same purpose: the sun as a directional tool; traffic cues; traffic patterns; sense of smell; familiar and unfamiliar sounds; and landmarks found with the cane. All of these skills—listening, feeling sun, locating objects with a cane, and quickly assessing the situation—must be taught. Who knows these skills better than a person who depends on them daily for normal, safe, and efficient travel? This is not to say that every independent blind person can teach

cane travel. It is, however, true that a capable teacher who is a good independent cane traveler by normal practice, can impart skill and knowledge to another blind person.

It is very important that the blind instructor go on travel routes with any new student for the first several trips, then observe the student very closely, especially at key trouble spots. There are those who would say that having to do so much walking is a problem for a blind instructor. A sighted instructor can watch the new cane user from a distance or hop in a car and observe the student in air-conditioned or heated comfort, while the blind instructor is out there with the student in all types of weather conditions, mentoring and tracking the new cane user. The blind instructor, since he or she is right there, can much more easily and quickly communicate with the student when necessary. Initially, it is imperative that constant communication occurs to let the student know the types of landmarks to look for, reminders to listen to traffic, how to cross parking lots, and so forth. Therefore, what most sighted specialists would feel is a problem, I consider an advantage. Many of these skills must be reinforced more than once, sometimes more than just orally. Often a hands-on method works best. The blind instructor is there to give immediate help and advice.

The biggest problem that sighted specialists perceive for blind instructors is that we cannot see the environment in front of the student to protect him or her from tree limbs, construction, or other barriers. Both the blind and sighted cane instructor plan travel routes that will be used for teaching travel techniques to the new cane user. It should be noted here that much travel in our daily lives follow highly known routes—to work, to school, and to shopping areas—that become fairly predictable travel routines to blind cane users. I do not believe these occasional obstacles to be a big problem. Again, it is my opinion that this is a philosophical difference: Sighted O&M specialists generally are abstract and theoretical or have a protective attitude toward

blind students, whereas blind instructors teach by using concrete, practical, and realistic approaches and examples.

Sighted specialists seem to believe that blind people need to be protected and are not able to do much really independent traveling. Blind instructors are independent cane travelers, and there is no doubt in their minds that blind students can be taught by other blind persons to be just as good, or better than, the instructor. Realistically, occasionally there will be a branch in the way and a blind traveler might bump it, or there might be construction along the way. The student must learn how to identify these things and how to deal with them. It is an advantage to travel in real-life situations during training in order to learn to use problem-solving skills. If a blind student is protected from real-life experiences, he or she will certainly not be able to travel independently. This is true because the protective, sighted instructor will not prepare the student to handle these environmental threats, and the student will then believe these obstacles cannot

Sighted specialists seem to believe that blind people need to be protected and are not able to do much really independent traveling.

be handled by a blind person. If students face these things during training they will learn that they can face and master any travel situation that might come their way, at any time.

Blind students at first are frightened and need much encouragement. Knowing that other blind persons are using

canes to capably and efficiently move about can make a big difference in the mind of the frightened student. When confronted with new situations, all of us, blind and sighted, look for role models. The blind instructor can be that role model to the new student.

To state my views succinctly: The biggest problem facing a blind cane travel instructor is a misunderstanding of alternative methods of teaching cane travel and the almost constant discrimination by sighted peers. Blind cane travel instructors are told they cannot do the job, in spite of their competence in using the white cane and the many successful independent cane travelers they have taught. While some blind people overvalue the convenience of vision and are unaware of the power of methods used by blind people, most blind people prefer being taught by a blind instructor, because they have confidence in their instructor's ability and they know their instructor's skills are tried and true and are used daily by thousands of other blind people.


Being constantly criticized and told that you are limited in what you can do because of blindness can become a real problem. However, the proof that you do know what you are doing is witnessed in the success of the many blind independent travelers taught by blind instructors. This argument is supported by comparing the travel skills of the more protected and sheltered blind persons taught by sighted O&M specialists. I am again not saying that cane travel instruction, as a profession, should be limited to blind instructors. I am saying that we, as blind persons have very valid methods that should be looked at on their own merits. The alternative methods used by blind instructors are just as sound as the usual prescribed certified methods of cane travel instruction advocated by sighted O&M specialists.

Finally, an ongoing problem for blind instructors is that they are not fully certifiable by the Association of Educators and Rehabilitators of the Blind and Visually Impaired (AER). Because our methods are different, blind instructors are barred from the higher financial

benefits paid by many of the state and private agencies to sighted O&M specialists. I look at some of the advertisements for O&M specialists and the money looks wonderful. I and other blind instructors cannot obtain these jobs simply because we do not meet the requirements set up by sighted O&M specialists (who teach in college and university programs), although we have helped hundreds of blind people to achieve true travel independence.

I realize this article does not discuss problems blind instructors have in teaching cane travel. This is because after searching my mind and heart I honestly do not believe there are many

Blind students at first are frightened and need much encouragement.

problems that we, as blind instructors, fail to share with sighted instructors. I have been as honest as I know how to be in discussing my cane training methods, based on my 12 years of teaching these methods both in a metropolitan city with buses and subways and in a small town with cabs and walking. The most prevalent problem encountered by blind cane travel instructors is the dichotomy in the philosophy of blind, noncertifiable instructors with that of most sighted, certified instructors. If this discrepancy in philosophies could be eliminated, there would be more candidates to fill vacancies in cane travel instruction, and the availability of more cane travel teachers would provide more opportunities for blind people to learn independent cane travel. 

Technology as a Support System for Orientation and Mobility

The development and application of technology for orientation and mobility has a long history covering the postwar period. Although some early endeavors envisaged systems that might replace the cane or dog guide, more recent efforts have focussed on devices and systems designed to supplement and provide a support system for these basic mobility tools. The present paper is an overview of past, present, and future technologies as a support system for orientation and mobility.

John Brabyn, Ph.D.

bility aids than previously thought. The recent burgeoning of technology addressing the orientation or navigation aspect of mobility, and the accelerating pace of technological development in society at large, will provide steadily improving opportunities in this field, almost certainly leading to more pervasive adoption by blind consumers of technological adjuncts to their traditional mobility aids and techniques.

Mobility Focus

The era following World War II saw the widespread employment of the long cane as a primary mobility aid for blind people. The war stimulated radar, sonar, and other electronic technologies which, with the later advent of the transistor, could be reduced to a size that led to the development of devices that were small enough for a pedestrian to carry. By the sixties and seventies, a plethora of devices intended to assist blind pedestrians were developed at least to the prototype stage (Brabyn, 1985). These developments used two main sensor systems; sonar and video cameras. During this era, most of the technology development focus was on the *mobility* aspect of the "orientation and mobility" problem. The various sensor and display systems were intended to provide the blind pedestrian with information on the presence, range, direction, and, sometimes, the nature of the objects immediately in front of him. The list of such electronic travel aids is long, and will not be treated in detail here. This research has been augmented by other studies of mobility technique and performance, such as the optimization

of long cane technique, the avoidance of obstacles, maintenance of a straight path, and so on.

Obstacle Detectors

The most popular method of obstacle detection has been the transmission of ultrasonic waves and the decoding of received reflections to sense the presence and sometimes the range of an object in the travel path. Many obstacle detection devices of varying types have been developed. Some, such as the *Mowat Sensor* (Pressey, 1977), are hand-held devices which can be aimed in the fashion of a flashlight. In the case of the *Mowat Sensor*, tactile feedback on the range of objects within the beam is provided using vibrations whose frequency increases as the object comes closer. Another class of devices, such as the *Russell Pathsounder* and more recently developed variations, are worn around the neck, and provides vibratory or auditory feedback on obstacle range in discrete distance increments. These devices are sometimes referred to as *clear path indicators*; they are intended to indicate whether the user has a clear travel path in front of him.

None of these devices is intended to replace the user's primary travel aid; for one thing, detection of low-lying objects, path edges or dropoffs is not reliably within the devices' capabilities. An exception is the *Laser Cane* (Nye, 1973), which incorporates laser sensors within the long cane itself to detect objects ahead of and above the user, and

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The problem of blind orientation and mobility is one that has fascinated engineers and technicians for many years. There has been a checkered history of many unique and innovative solutions being proposed and developed, with varying degrees of success. Although no technology has to date succeeded in being universally adopted by blind consumers, recent surveys (Blasch, 1994) have found that more use is being made of existing mo-

signal him via vibratory tactile feedback built into the cane handle. Through a novel configuration of transmitting and receiving elements, this device can detect dropoffs in front of the user.

Environmental Sensors

As implied above, developments in electronic mobility aids have ranged from simple obstacle detectors to sophisticated information displays that could also identify objects, textures, and flow patterns. In the early years, the most sophisticated device that became commercially available was the *Kay Sonic Torch* (Kay, 1964), with a handheld device that used an FM sonar with an information-rich auditory display. The auditory information was presented to the user via an earphone. Range was indicated by the pitch of the auditory signal and information about the nature of the objects detected was provided through the timbre of the sounds. In this type of system, environmental objects such as picket fences, hedges, and poles each caused characteristic sound patterns. Even differences in surface textures of the ground in front of the traveler could be detected, such as the difference between the hard sidewalk surface and the adjacent grassy verge.

Because of these characteristics, the Sonic Torch could be used as a primary mobility aid, replacing the cane or dog guide. Subsequently, Kay adopted a different approach that definitely retained the cane or dog as the primary aid and supplemented it with a version of the sonar sensor worn on the head. This new device (Kay, 1974) was later commercialized as the well-known *Sonicguide*, perhaps the most influential electronic mobility aid produced to date. The *Sonicguide* provided a similar display of range and object identification information to that of the Sonic Torch, but employed a wide "field of view" in

place of the narrow Sonic Torch transmitter beam and two receiving channels that gave a binaural display with interaural intensity difference as a directional cue. Thus, with suitable training, the user could obtain information not only on the range and nature of objects, but also on direction and motion flow patterns.

Other notable developments in the field of ultrasonic mobility aids, not easily categorized as obstacle detector or environmental sensor, include the incorporation of multiple ultrasonic channels under microprocessor control as in the *Pathsounder* device (Russell, 1965), which assists such functions as finding a safe path through a gap such as a doorway.

An entirely different approach to sensing nearby objects was taken by Collins, Bach-y-Rita, Scadden, and others (Collins et al., 1977) in the pursuit of tactile display of image information ob-

readily understandable. This led to several other experimental developments, such as presentation of a scanning sonar image (much like a ship's radar display) on the skin (Brabyn et al., 1981). Ultimately, commercial realization was impeded by system cost and complexity, but the tactile presentation of information has received continuing attention, especially as an educational aid to present visual concepts through another medium.

The Orientation/Navigation Problem

Orientation and navigation refer to one's ability to know where one is in the pedestrian environment and to locate waypoints, landmarks, and destinations. The primary mobility aid such as the cane or dog guide—supplemented by hearing and echolocation cues—have proven to be excellent and most difficult to improve upon technologically for the "mobility" part of the equation: finding and following a safe path through the immediate environment. The "orientation" component, however, offers considerable potential for technology to perform functions that the traveler might not otherwise be able to perform and support his primary mobility aids and skills. In many situations in everyday travel, such as transportation facilities, crossroads, shopping malls, and parks, a major unsolved problem for a blind pedestrian is to know ex-

actly where he is, where his destination is located, and how to get there from where he is.

Of the many devices which have been developed (ultrasonics or other transmission media) to sense the adjacent environment in front of the blind pedestrian, some can also be used to assist orientation and navigation. This is especially true of those like the *Sonicguide* that have the capability to help



Blind traveler uses remote signage in rapid transit station to locate and recognize signs and landmarks.

tained from video cameras. This approach utilized optical to tactile image conversion, which provided a point for point representation of a video camera image on the skin using a large two-dimensional array of electrical or vibratory (mechanical) tactile stimulators. This approach, like the *Sonicguide*, presented the user with an information-rich display, to the point where it needed to be simplified to make it more

in identifying landmarks to assist the user in establishing his position. By detecting a consistent sequence of such landmarks, the user can reinforce his internal map and gain an improved concept of his exact location. The type of information presented, however, is by its nature generic, in that all poles cause similar sounds, whether they are bus stops, lamp posts, or traffic lights.

The recent emergence of new navigation-related technologies in military and civilian applications, coinciding with legislative activity and governmental program initiation in North America and Europe, has now definitely shifted the focus of technological development to the orientation aspect of travel. At the same time as new technologies are becoming possible, governmental and regulatory activity has improved the prospects that there will be a viable market—or even a mandate—for navigation systems to make the environment accessible to the blind and visually impaired population. In the United States, for example, there is a mandate within the Americans with Disabilities Act (ADA) to provide access to public facilities. For a blind individual, the term “access” in this context means largely the ability to *find* the facility; braille and raised print signage do not achieve this goal since the blind individual must search around to find them. Thus, other forms of navigational assistance are needed.

Some of the different approaches to this problem that either have been or are currently being investigated include various forms of remotely readable signs or labels for the environment, dead reckoning systems, map reading technologies, and absolute positioning systems.

Remotely Readable Signs

The ability to read signs and recognize environmental objects, facilities, and landmarks from a distance is key in efficient orientation and mobility. This can be dramatically demonstrated to a sighted individual traveling in a situation where all the signs are either missing or in a foreign script. Ubiquitous signs comprise a menu of choices for

sighted travelers, confronting them with the options available at any given point in their travel. In a sense, they also act as a form of memory; signs remind travelers about important characteristics of the environment.

The first system of remotely readable signs for blind users to be developed was the *Talking Signs System* (Loughborough, 1979). The concept was to provide coded infrared transmitters at any location where a sign or label is desirable, so that a blind pedestrian with a suitable receiver could read it at a distance in the same manner as sighted travelers read printed signs. Talking signs transmitters continuously transmit signage information from infrared Light Emitting Diodes (LED's) located at the position of each sign or labeled location. The infrared signal is decoded by a handheld receiver carried by the blind individual to produce a directionally selective voice message. The direction selectivity is a characteristic of the infrared message beam, so that the intensity and clarity of the message increases as the sign is pointed at or approached. Thus, the individual using the device can get feedback about his location relative to the goal as he moves towards it. The signs are light and small, easy to install, consume very little power, operate indoors and outdoors, and are easy to program with human voice or synthesized voice messages. Because different signs have different functions, the range and angle of coverage of each sign is adjustable.

In recent years, the Talking Signs System has become commercially available, and demonstration installations include the Carroll Center for the Blind, the Lighthouse in New York, the Washington, DC, Metro, the Texas School for the Blind, and a number of facilities in San Francisco, such as the Powell Street Muni/BART subway station, the five-way street intersection above it, the public library, and public toilets. Many other installations are under construction or planned and similar systems are under development by companies and researchers in the United States and Europe. The system has been evaluated in a number of psychophysical

studies (Brabyn & Brabyn, 1982, 1983; Schenkman, 1986; Bentzen, 1993) and reception by blind users has been enthusiastic. Clearly, remote signage technology can provide unique advantages to the blind or visually impaired traveler in allowing him to locate and recognize signs and landmarks from a distance both indoors and outdoors.

Remote signage and *interactive environment* systems using various forms of radio transmission as a medium have also been proposed and developed. The first was a system developed by Kelly (1980) utilizing garage door opener technology. The concept in this case was to place receivers at the locations of the signs or desired landmarks (restrooms, lifts) and to have blind persons interrogate the receivers with handheld transmitters. The use of radio transmission has since been explored by others, such as System and Main (1991), Urband et al. (1992), Fanmark Technology Corp, and the RNIB REACT system. Variations on these themes include the *responsive environment* concept and similar approaches using passive credit card sized tags which can absorb and retransmit appropriately coded radio signals from a suitable computerized transmitter (Jaffe, 1992). Proximity-triggered talking signs have also been tested (Jones 1991). Another system, known as *Verbal Landmarks*, emerged in 1992. This used radio frequency transmissions from loops embedded in the surroundings of doorways to identify entrances and other waypoints. A user's receiver within range of the Verbal Landmark transmitter announces the location as a verbal message.

In 1993, the American Council of the Blind proposed an evaluation of the infrared- and radio frequency-based technologies. The resulting comparison study (Bentzen, 1993), in which examples of both were tested in a hotel setting, showed a preference for the infrared-based technology in terms of objective travel measures (time to travel and travel distance) and in subjective user opinion. This difference is largely due to the innate ease of localization and beam pattern control using infrared transmitters and receivers.

Dead Reckoning Systems

Another approach to orientation and navigation is the use of *dead reckoning* navigation to establish the pedestrian's position. Dead reckoning utilizes knowledge of a starting point, coupled with input from sensors, such as a compass and pedometer or other form of distance measuring device, to establish present position. Once position is established, reference can be made to computer stored maps or route descriptions to give the user a large amount of information about his surroundings and his desired route. A test of the potential of this approach was carried out by the author and others (Milner & Gilden, 1988; Jampolsky, Brabyn, & Gilden, 1989). The sensor technology evaluated consisted of a K band Doppler radar to measure distance traveled in combination with a flux gate compass for directional information. The sensors were ultimately to be coupled to a micro-computer which would incorporate a stored map of the area of interest, along with considerable descriptive and route instruction information to guide a user from anywhere within the mapped area to anywhere else. In the initial, simplest embodiment of the system, however, route information would be prerecorded on a cassette tape rather than a computer. To record a cassette for a given route, a sighted person would accompany the blind traveler and push a button to put a code on the tape as each landmark is reached. The sighted guide would also record a verbal description of the landmark (bus stop, corner, etc.) as well as a running commentary on the points of interest in between landmarks as the route is traversed.

The basic technology for this type of system was found to be feasible in 1988, when simulation results from tests with a dozen blind subjects were extremely positive (Jampolsky, Brabyn, & Gilden, 1989); at the time, however, the collaborating manufacturer did not feel the commercial aspects of the project would warrant further expenditure. When these explorations were made, the available technology for position sensing, electronic map storage, and high

power portable computing were considerably less advanced than is now the case; it would now be possible to apply many of the same concepts while achieving greater positioning accuracy and lower cost.

Global Positioning Systems (GPS)

The advent of the highly accurate *Global Positioning System* (GPS) has led to new experimentation and development work on blind navigation. GPS, originally developed for military purposes, utilizes a network of satellites in very precise orbits around the earth transmitting precisely timed microwave signals. Suitable receivers on the earth's surface receiving information from three or more satellites can use the signals to give an estimate of longitude, latitude, and altitude. Codes made available for civilian use allow positioning accuracy to within approximately 100 meters with "selective availability" and 15 meters without. Greater accuracy (1-15 meters) can be obtained with *differential* GPS, utilizing an additional transmitter placed nearby on the ground.

Experimental and developmental work on applying this system to assist blind travelers has been undertaken by several researchers and companies, including Loomis and Golledge (1993), Bornschein, Balachandran, Frank, and Arkenstone, Inc., and others. The Arkenstone system has been pursued to the stage of a commercial product, *Atlas Strider*, which combines a talking map system specially designed for blind users integrated with information from a GPS receiver.

In conjunction with suitable stored map information, computing power, and carefully designed information display interface, GPS technology provides many possibilities for providing a wide variety of orientation and navigation support to a blind traveler. It can be used alone as a position sensor or combined with other dead reckoning sensors to provide greater accuracy. It could be used to provide the type of verbal, waypoint, landmark, route instruction, and ongoing commentary described in the above section on dead

reckoning systems, without the complication of regular recalibration.


GPS is ideal for providing approximate position estimates in open areas. Due to the line-of-sight nature of the microwave signals used by the system, accuracy and operation may be compromised in many areas of interest to the blind traveler, such as narrow downtown streets lined with tall buildings, indoor areas (hotels, office buildings, and shopping malls) and underground facilities (e.g., transit stations). Due to limitations in accuracy, precise location by the blind traveler of vital points in public areas such as restroom doorways, ticket machines, public telephones, and subway entrances may require combining with other technologies. This suggests the future desirability of combinations with other technologies in any comprehensive O&M support system.

Future Possibilities

A number of other approaches to the design of orientation and navigation systems are possible, and some have been tested. Methods utilizing forms of image processing or artificial recognition of environmental features have been explored by several investigators following the pioneering work of Collins (1982). Systems of this nature could conceivably be sophisticated enough to locate and read print signs and recognize objects such as public telephones and many other features of the environment. Variations on satellite navigation systems have been proposed that eliminate some of the restrictions on GPS operation. Various forms of electronic map reading technologies have been or are being investigated, and these can be interfaced with locating and positioning systems. Various inertial navigation systems have been investigated and may provide an adjunct to other sensors in increasing accuracy and directional information. It can be expected that developments in technology well beyond the field of sensory aids will provide yet more possibilities for enhancing the existing approaches or providing new alternatives.

Discussion

With few exceptions, all of the technological developments past, present, and future in this field envisage the technology in question as operating in support of the blind traveler's primary mobility aid and skills. Each of the major technological approaches to providing useful support information to the blind traveler has advantages and disadvantages. Ideally, technology should provide the traveler with the supporting information he/she wants and needs, in a convenient, easily understood manner. The option of *not* receiving the information (receiving it only when it is wanted) is one major factor in these considerations. Ultimately, the user should have available enough information to allow effortless, stress-free travel with direct location (without the need to search tactually) of the key points of interest (whether they are doorways, drinking fountains, telephones, ticket machines, or others). And, of course, the ideal system would have universal coverage of all areas the user may wish to go.

Because no system presently meets all these requirements, the advantages of combining different approaches should, in the author's view, be explored. The pinpoint accuracy, user convenience, and directionality of remote signage systems, for example, could be combined with the approximate vicinity locations and verbal commentaries obtainable from suitable computer-interfaced GPS and dead reckoning-based technologies described above, also giving coverage of those areas where remote signage is not installed. Many permutations and combinations are possible and the continuing trends towards miniaturization and cost reduction in electronic systems makes consideration of combinations of technologies more feasible. These trends also make it likely that more and more users will gradually take advantage of the supplementary travel information that technology will provide. 

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Making Mass Transit User-Friendly for Blind Commuters

While vital to the quality of life in a large urban environment, mass transit takes on particular importance to blind people leading active, productive lives. Using practical, straightforward techniques, blind persons travel safely, confidently, and competently on any mode. Blind transit riders can use sounds, feel, and other physical characteristics as excellent landmarks, especially on rail transit. However, some modifications are needed for mass transit to function optimally for people who are visually impaired. This article discusses a number of the problems.

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the built environment, particularly regarding raised, truncated dome detectable warnings, ostensibly to alert blind persons approaching or walking along platform edges.

Technological advances in the transit industry, such as automatic fare collection and passenger-activated doors, highlight the need to work with blind people and resolve information access and travel issues. With imagination and a positive attitude about blindness, the industry can continue making mass transit the blind person's car.

Introduction

Increasing awareness of and emphasis on disability issues quite logically leads to questions about the population percentage or number of people who might use related services, programs, and facilities. The blind community makes up a very small portion of the population at large, as well as a small portion of the estimated population of over 40 million people with disabilities. Federal population statistics roughly estimate the number of blind people at two per thousand, or about 500,000 nationwide. This number, however, gives no indication of what percentage of blind people ride transit.

At best, the transit industry has very sketchy, incomplete data regarding possible numbers of blind riders. Since 1975, the Metropolitan Transportation Authority (MTA) in New York has issued 13,600 half-fare cards to blind riders, about 80 percent of these in New York City. MTA, however, has no count of blind persons who ride but have not applied for half-fare cards. Baruch College Computer Center for the Visually Im-

paired, which is producing a limited number of subway maps for MTA, estimates that about 5,000 blind people use the subway daily.

ADA Accessibility Guidelines (ADAAG) do not have a quantitative threshold, either in terms of population percentages or actual numbers, at which they become effective. This discussion, therefore, will address transit issues pertinent to blind passengers from a qualitative rather than quantitative perspective. Most notably, the National Federation of the Blind (NFB) has developed a decades-long history of advocacy, at the national, state, and local levels, for more and better transit service and continues to advocate vigorously for rehabilitation services based on the positive philosophy that, given proper training and opportunity, blind people can attain self-confidence and competence necessary to lead active, productive lives.

Methods and Techniques

Environmental Cues as Landmarks. Whether traveling with canes or dog guides, blind people use many practical, straightforward techniques and methods to ride rail transit safely and effectively. By listening, they ascertain the direction from which the train approaches, determine whether they board toward the front or rear, and locate the opening doors. Not seeing directional and informational signage, they maintain orientation by paying attention to compass directions, espe-

Ongoing implementation of the Americans with Disabilities Act (ADA) has raised issues related to verbal and written communication—Braille and raised print or audio/video signs and publications in “alternative formats”—with blind transit riders. ADA also has raised controversy among blind people about modifying

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cially while walking through stations and riding trains as they round curves or switch tracks. The physical characteristics of the railway, sounds and feel, make excellent landmarks (e.g., the echo and louder sound of subway tunnels; the vibration and slight rocking when riding through track switches; the crossing over from one track to another, as track switches guide the train along its route at terminal stations or junctions; the "clickety-clack" of "jointed rail"; the resonance of elevated structures and bridges; the smooth, quiet ride of welded rail, usually in sections of several hundred feet; the quiet ride of "ballasted track," with rails mounted on wooden or concrete ties set in crushed ballast rock). Blind transit riders can note these landmarks along the way, just as sighted drivers would note buildings or street names. Continuing this analogy, riding on the right-hand track of a two-track railroad compares with driving in the right lane of a two-lane road. On a center platform station with two tracks, the passenger would face the desired direction and take the train on the right. Likewise, riding on the right outside or inside track of a four-track operation corresponds to driving in the right outside or inside lane of a four-lane road.

Canes

Blind people who use canes extend them to find the platform edge, walk straight, and keep a safe distance from it. Thus, they avoid the many fixtures and facilities typically installed toward the center of platforms: windbreaks on outdoor platforms, stairs, escalators, elevators, supervisor booths, trash cans, newspaper stands, advertising or informational signage, or kiosks and benches. Alternatively, some older subway stations have support pillars every few feet near platform edges. Blind people can locate these pillars with canes and walk a straight line just inside them. Canes also enable blind people to distinguish open doorways from the spaces between cars, as well as to negotiate the gap between platform edge and cars. This method works, regardless

of whether trains have between-car barriers, such as gates or springs. Cane tips, especially metal ones, make an excellent, sharp, tapping sound on hard surfaces, the echo from which provides excellent auditory cues to blind people walking through stations. These auditory cues become particularly useful on island platforms where other passengers insist on lining up and waiting along the edges, keeping blind persons from using them as a guide.

Dog Guides

Blind people who use dog guides avoid passengers and fixtures because dogs have received training to guide them around obstacles. They also keep a safe distance from the platform edge, because dogs respect the dropoff beyond it. When boarding trains, dogs guide their users away from spaces between cars and toward open doors.

Information Access in Chicago

Publications in Alternative Formats. The Chicago Transit Authority (CTA) now produces and distributes several publications in such alternative formats as Braille, computer disk, large print, and audio cassette. One publication, CTA's *Rail Transit Guide*, covers all the rail routes, listing station name, street address coordinates, numbers of connecting CTA and Pace suburban bus routes, as well as information about connecting Metra commuter rail and other transportation services.

Informational Announcements. Blind people have stressed the importance of bus operators calling stops. Years before ADA, CTA's bus operator training and rules promoted the positive notion that announcing stops benefits all riders, while providing more accessible service to blind people and others with disabilities. More than 1,400 buses which CTA received in the nineties have public address systems.

All CTA rail cars have had public address systems since the fifties. All CTA cars in regular service now also have outdoor speakers mounted near passenger doors enabling train personnel

to make announcements directly to waiting passengers on the platform and, incidentally, focusing their attention on the location of doors. Conductors or operators advise passengers regarding closing doors, standing clear of doors, priority seating, and no smoking or radio playing. They announce the train's run number, all station stops, transfer points to other rail lines, delays, reroutes, station closings, and major points of interest. In addition, for all rail cars acquired from the sixties to the eighties, CTA is implementing a *Communications Enhancement Program* in which intercoms will be used for passengers to talk to train operators; automated stop announcements will have a digitally recorded professional announcer's voice for standard announcements; the operator will make special announcements, such as express runs; and cars will have light-emitting diodes (LED's) mounted on the interior of the destination sign boxes to signal express runs, especially for deaf and hearing-impaired riders.

Audio/video station signs automatically will announce direction of train arrival and eventually may give delay information. In the winter and spring of 1995, CTA conducted a demonstration at the Merchandise Mart Station using different male voices for southbound and northbound service. CTA is currently evaluating various systems for station announcements with prerecorded voices and electronic visual display.

Braille and Raised Print Signage. CTA installed Braille and raised print numbers in all buses, on the passenger side of the driver's barrier and on the panel behind the rear door, facing the stairs. These numbers enable blind riders to identify particular buses when reporting incidents. The two new series, delivered in 1995, have number plates, with white digits on a black background, mounted on stainless steel panels. CTA has also put these numbers on older buses, using stainless steel plates with no color contrast.

CTA train cars have their numbers written in raised print and braille, 5 feet from the floor on the panel to the right, as passengers leave the train. Riders may note the car number to report the condition of the car or activity on the train. The

newest cars, in use on the Brown, Orange, and Yellow Lines, have intercoms located toward the end of each car near the wheelchair positions and operators' cabs. Passengers may use these intercoms to communicate with train personnel. These intercom positions also have raised print and braille instructions, as well as car numbers.

CTA planning, architectural, and engineering staff have explored messages, materials, and methods of installation of Braille and raised print signs in rapid transit stations. Suggested locations include: entrances; exits; points of level change; decision points, such as diverging paths toward side platforms; and boarding areas. In 1997, CTA purchased over 300 zinc signs with Braille, raised print, and color-contrasted letters and a number of smaller signs for customer assistant call buttons in rail stations.

Truncated Dome Detectable Warnings

Current ADA guidelines require installation of raised, truncated dome detectable warnings along the edges of train platforms.

Some systems, including Port Authority Trans-Hudson (PATH), Dade County Metro in Florida, and Bay Area Rapid Transit (BART) in San Francisco, have installed hard rubber raised truncated dome tiles along all their station platforms.

Others, such as New Jersey Transit (NJT), MARC/Mass Transit Administration in Maryland, CTA and Metra in the Chicago area, New York City Transit Authority (NYCTA), and Long Island Railroad (LIRR), have installed these tiles, made of fiberglass or other materials, at many key stations (i.e., transfer points and terminals). These and other rail systems plan to install raised truncated dome warnings in future new construction and major reconstruction projects.

NFB has long held that public entities, such as transit systems, would benefit blind persons more by allocating limited resources for general improvements than by wasting such dollars for unnecessary, expensive modifications of

the built environment. NFB further asserts that such expensive modifications perpetuate negative myths about blindness, among blind and sighted persons alike. The following citations of NFB resolutions, published in *The Braille Monitor*, include month, year, and page number; resolution number; and a brief synopsis:

1. August–September 1995, p. 496, 95–11. Calls upon agencies having responsibility for guidelines, regulations, or enforcement of ADA to eliminate requirements for detectable warnings.

2. August–September 1994, p. 532, 94–12. Condemns Department of Transportation insistence to install truncated domes on subway platforms; commends WMATA's resistance to do so.

3. September–October 1993, p. 987–988, 93:02. Commends government agencies for abandoning support for detectable tactile warnings in traffic and architecture in favor of further study and expresses view of NFB that such warnings are not helpful to blind and may be harmful to everyone; it does not object to textured surfaces in general but objects specifically to raised truncated dome tiles.

4. September–October 1993, p. 997, 93–17. Urges Clinton Administration and Congress to provide findings and personnel to implement ADA.

5. September–October 1993, p. 997, 93–20. Commends American National Standards Institute for reflecting true needs of blind Americans by excluding any reference to detectable warnings in its published standards

6. September–October 1993, p. 488–489, 92–06. Updates NFB's position on audible traffic signals.

7. September–October 1993, p. 489, 92–07. Opposes research on detectable warnings for the blind in architecture, on sidewalks, and so forth.

Recognizing this perspective and experience, skepticism and opposition to raised truncated domes has increased among government standard-setting bodies, such as the American National Standards Institute (ANSI), which removed the detectable warning requirement from its list of accessibility standards in 1992.

Virginia Railway Express (VRE) runs rush hour commuter train service on two main lines connecting many communities in Northern Virginia with Washington D.C. Regular riders report that during winter months snow and ice accumulate between the raised, truncated domes along platform edges. Conductors point to this hazardous condition with the caution: "Watch your step; that first step is slippery!"

In 1992, CTA convened a task group to seek comment and suggestions from the blind community. Significantly, most task group members, blind and sighted alike, complained strongly that truncated domes endanger passengers by catching their cane tips and heels of shoes when they walk along platform edges or board trains. Reflecting these concerns, CTA initially installed raised truncated dome borders along the entire length of platform edges at only three completely rebuilt stations, conducted demonstration projects, and accomplished only partial installations of raised truncated domes at two other stations as of spring 1995. Materials included metal, fiberglass, and concrete, but not rubber. In May 1996, CTA reopened its Green Line, which it had closed in January 1994 for complete reconstruction. All newly rebuilt stations have raised truncated domes. Several downtown subway stations, renovated in 1995 and 1996, as well as two new elevated stations on the Loop "L," now have raised truncated domes. Other stations, new construction and reconstruction projects designed and funded before the effective dates of the ADAAG, were built without such materials, even though the work took place during the nineties. CTA is now installing raised truncated domes at these as well as at ADA "key stations."

In 1994, the Washington Metropolitan Area Transit Authority (WMATA) received an extension on the installation of truncated domes at key stations. Since then, WMATA actively has analyzed this issue and has sought public participation. It installed two demonstration sites, one underground and the other outside, containing several detectable warning designs and materials,

including truncated domes. The Battelle Mèmorial Institute conducted a *Platform Edge Study* of a variety of 24 inch wide detectable warning textures and materials. Entitled, *The Impact of Transit Station Platform Edge Warning Surfaces on Persons with Visual Impairments and Persons with Mobility Impairments*, it concluded, in part: "In terms of stopping distances for blind participants, no statistically reliable differences between warning surfaces were noted." Battelle's second study, entitled, *Detectability of 18-in and 24-in Flame Finish Granite Warning Surfaces for Use in Transit Stations*, concluded, in part: "In terms of mean stopping distances from the platform edge, for participants who are blind or have low vision, no practical difference between 18-inch and 24-inch Flame Finish warning surfaces was noted."

WMATA held public hearings in March 1995 regarding its proposal to request equivalent facilitation for the current granite platform edge. Most testimony strongly supported this position. WMATA's news release, issued the following month, entitled *Metro to Keep Existing Platform Edge, Federal Transit Administration Decides in Favor of WMATA Request*, begins: "The Federal Transit Administration (FTA) announced yesterday that the Washington Metropolitan Area Transit Authority (WMATA) would not be required to make any structural changes to the platform edges in its metrorail system."

In May 1995, the Architectural and Transportation Barriers Compliance Board (ATBCB) considered NFB's petition to rescind the "raised, truncated dome" specification. CTA, WMATA, and Southeastern Pennsylvania Transportation Authority (SEPTA), all of which operate extensive rail systems, submitted supporting petitions, calling for the retention of existing platform edges instead.

James Gashel, NFB's Director of Governmental Affairs, reports that, in response to these petitions, ATBCB initiated a review process to consider whether to remove or modify this provision. It passed a resolution directing its Communications Subcommittee to

develop a "performance standard" reflecting the ultimate goal, instead of the current "descriptive standard" requirement.

In 1997, Battelle conducted additional studies for WMATA. Following is an excerpt from its *Executive Summary*:

"The objective of this work was to determine whether a warning surface for visually impaired persons, proposed by the Washington Metropolitan Area Transit Authority (WMATA) for use at their key and new rail transit stations, satisfies the equivalent facilitation provision allowed by the Americans with Disabilities Act Accessibility Guidelines (ADAAG) specification for detectable warnings." A public hearing to receive and consider comments on WMATA's proposed warning surface was held in October 1997.

Fare Automation

The transit industry increasingly has turned toward automatic fare collection. New rapid transit systems of the late sixties and seventies have brought automatic fare card vending machines and ticket activated fare gates into common use. Some older rail systems also have followed this trend. In 1968, automatic fare collection came to the Chicago area for the first time when the Illinois Central instituted an automatic fare card system on its commuter rail service (Metra Electric).

CTA implemented its *Transit Card*, an automatic fare card system for its busses and rail systems, in spring and summer 1997. Passengers can either buy cards with predetermined value at various food stores and other retail outlets. They also can buy *Transit Cards* or add value to existing ones at *Transit Card* vending machines at rail stations. Monthly passes—at a reduced rate for people with disabilities—allow unlimited riding. CTA is proceeding with a pilot program for a smart card which uses radio frequencies and activates fare equipment when the passenger brings it close to the "target" (or antenna) on the turnstile or bus fare card machine. Initially, CTA has begun marketing this card as a monthly pass for riders with

disabilities, especially those with manual dexterity problems preventing them from inserting cards in slots. CTA is now developing a stored-value or debit card version of the smart card.

NYCTA is also implementing *Metro Card*, a debit card system which enables passengers to transfer between bus and subway for a single fare.

New light rail systems of the eighties and nineties commonly feature European style barrier-free stations with inspectors riding trains and checking tickets. All these rail systems now have or will have automatic fare card vending machines.

How has the transit industry addressed information access for the blind passenger who previously asked a readily available fare collecting employee the essential question, "What's the fare?" On a bus or streetcar with a fare-box up front, the blind passenger, upon boarding, may ask questions of the operator about fares or transfers. On commuter trains with conductors who sell and collect tickets or handle cash fares, or at stations where agents handle currency and fare media, the blind person also may ask questions of personnel. Some rapid transit and commuter rail systems have station attendants, while others have telephones at ticket or fare card vending machines. Either way, personnel can assist passengers, blind and sighted alike, on operating these machines and using the fare media.

A blind person, purchasing a ticket at an unattended light rail station, with no Braille or speech on the vending machine and no telephone to call for assistance, can look for a passerby or fellow passenger to help, or otherwise board the train without a ticket and try to convince the fare inspector or police officer of the circumstance. Moreover, a blind person, riding a light rail train for the first time, might not know about ticket vending machines and thus would anticipate buying a ticket from a conductor on board, as on a commuter train.

The transit industry cannot consider assistance from the sighted public the primary method of information access to blind passengers using automatic fare collection equipment. In the inter-

est of common sense, as well as ADA compliance, transit systems must give blind passengers a way to pay fares independently. Some light rail and rapid transit systems have placed detailed Braille fare instructions on ticket or fare card vending machines. Writing these instructions on a panel of the machine poses the potential problem of giving outdated information unless the transit property updates the machines' hardware by physically changing the Braille information when fares change.

Depending on the variety of transactions that the fare structure offers, a blind person still may need assistance from a sighted person because, to date, these machines have had no synthetic speech. They give audible confirmation only by their mechanical operation, as they accept or reject currency and issue tickets. CTA's *Transit Card* program includes vending machines with Braille instructions and speech on demand for a particular transaction. This compromise keeps the machine from announcing every fare transaction, a particularly important security consideration for a passenger who may purchase a *Transit Card* with a large dollar amount in an inner-city station.

Light Rail Operation

Light rail offers an infinite variety of service possibilities between traditional streetcar and rapid transit or commuter rail. Boarding light rail cars in surface transportation resembles boarding buses, while boarding them on private right-of-way resembles boarding trains. In any event, all rail systems have certain common features.

A primary difference between the older style of streetcar service and modern light rail relates to boarding the car. The blind passenger, who usually boards the bus or streetcar, where the operator opens the front doors, as well as the rapid transit or commuter train, on which all doors open, might feel daunted at the prospect of locating buttons on the outside of cars to open doors. The transit system could alleviate this situation by having light rail train cabs equipped with door controls

which the operator could use if a passenger, blind or sighted, has difficulty opening the doors from outside the car. When doors do not open, passengers obviously do not step off the car, and the boarding blind passenger does not have these sound cues. In this instance, a subtle auditory cue might assist blind people while benefiting other passengers as well. Perhaps the same circuit that enables passengers to press the button and open doors could activate a soft bell or tone, located at the car door.

Alternatively, outdoor speakers mounted near doors similar to those on several systems' cars might serve a dual purpose. While alerting passengers to the location of doors, outdoor speakers can facilitate announcements of train direction and destination to waiting passengers at platforms where several routes stop or on outlying single track sections on which trains travel in either direction.

Linear Path


In the context of accessible design, transit planners have expressed the concern about incorporating clear, linear paths along platforms and through rail stations. A common sense design and approach benefits all passengers. As such, primary travel paths should have as few turns as possible, allowing passengers to move efficiently and directly between essential elements of stations. Whenever possible, these travel paths should run parallel with or perpendicular to major rights-of-way, streets, or tracks and platforms. For example, passengers can enter and exit stations and maintain their orientation more easily when fare controls—gates and/or turnstiles—face parallel with the direction of rail travel through stations. Clear, direct travel paths facilitate efficient passenger circulation across or perpendicular to the direction of travel in several situations: subway mezzanines, between entrances on or adjacent to sidewalks at street level, platforms beneath the street, concourses serving several platforms at major terminals, and grade crossings at light rail stops or commuter train stations. The most efficient linear

Paths along platforms depend upon station characteristics such as platform width and placement of support pillars, fixtures, and facilities of level change.

Transit Information

A telephone call to transit information, while important to anyone needing directions, becomes particularly important to blind passengers. When giving directions, transit information generally would advise a sighted person to observe the signs. A blind person, therefore, may ask for more specific information regarding services and facilities: location of bus stops with relation to intersecting streets, location and layout of light rail stops, and location of entrances and platforms of elevated or subway stations. In many systems, transit information operators have extensive personal experience with their routes and service areas, along with detailed schedules and maps. In some systems, transit information operators may refer blind callers asking detailed questions to staff who can give such information. For example, the Travel Information Center in Chicago sometimes refers blind callers with detailed questions to CTA Customer Assistance. As part of a multifaceted travel training program, WMATA has established *Mobility Link*, a hotline which blind persons and others with disabilities can use to receive directions more detailed than those available through Transit Information.

Conclusion

Blind people can provide the best solutions for their travel needs. The transit industry should take advantage of this valuable resource. With imagination and a positive attitude about blindness, we can make rail and other modes of transit viable, safe, and effective for blind people. The author's experience is by no means unique. Thousands of blind people throughout the country travel safely and confidently by mass transit every day. They are self-sufficient and independent and lead active, productive lives and consider mass transit the blind person's car. Let's get in and go for a drive! 

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NEW PUBLICATIONS AND FILMS

Students with Acquired Brain Injury. The School's Response.

Ann Glang, George H.S. Singer, and Bonnie Todis, Editors. Paul H. Brooks Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624. Tele: (410) 337-9580. FAX: (410) 337-8539. Softcover, 400 pages, \$29.95.

This book serves as an introduction and a practical handbook for working with children who have acquired brain injury. It describes a full range of issues facing this growing student population and presents strategies for improving the quality of the school experience for all children—regardless of the setting—from special education classrooms to fully inclusive programs.

Cognitive Learning Theory and Cane Travel Instruction: A New Paradigm.

Richard Mettler. Rehabilitation Services for the Visually Impaired, State of Nebraska, Department of Public Institutions, 4600 Valley Rd., Lincoln, NE 68510-4844. Softcover, 170 pages. \$10.

This treatise advances an alternative approach to the training of cane travel instructors. The training model used is grounded in what is termed "structured discovery learning." Recent developments in cognitive learning theory are applied to explain a way to teach cane travel which is in dramatic contrast to the teaching model which appears to currently dominate the field. By changing the focus from what the instructor knows to how the student learns, this book offers a new paradigm for understanding all aspects of the psychomotor skill of cane travel. The book argues that superior cane travel instruction results from cultivating the perceptual, cognitive, and motor skills of cane travel from within the student's immediate experience and within the student's locus of control. A second practical benefit from this new paradigm is a way to relieve this country's severe and long-standing shortage of rehabilitation professionals capable of teaching cane travel—result-

ing in large and growing numbers of underserved and unserved blind persons. The author states that the structured discovery teaching model for cane travel instructor training can easily be conducted at the local agency level, or at an educational institution—university, college, or community college—and can be completed in 3 months.

Affirmative Action in the Employment of Ethnic Minorities and Persons with Disabilities.

Jane Hodges-Aeberhard and Carl Raskin, editors. International Labor Office, ILO Publications Center, P.O. Box 753, Waldorf, MD 20604-0753. Softcover, 115 pages, \$18.00, plus postage and handling charges of \$4.50 for a single book and \$1.00 for each additional book.

This book, using the insight of eight country studies, describes current trends in the implementation of affirmative action in employment for ethnic minorities and persons with disabilities, whether it be by legislative enactments, general policy measures, voluntary programs, or a mixture of these elements.

The Encounter.

Richard Mettler, producer. State of Nebraska, Department of Public Institutions, Division of Rehabilitation Services for the Visually Impaired, 4600 Valley Rd., Lincoln, NE 68510-4844. Available in both English and Spanish (El Encuentro) language versions from Carmichael Audio-Video, 1025 South Saddle Creek Rd., Omaha, NE 68106. Telephone: (402) 556-5677. VHS Tapes, \$8.50. Running time: 11:15.

Misunderstanding about vision loss is found mainly in the presumption that blind people are not able to engage in everyday activity without sighted direction. This results in a pattern of being overly helpful, even when assistance is not needed. The motivation here is well-intentioned, but the effect perpetuates mistaken beliefs about the ability of blind people to get on in the world in-

dependently. This limits opportunities in the mainstream of community life, including school and the workplace.

This video challenges this misunderstanding, using humor to expose common myth and misconception so the viewer can reflect on vision loss clearly. The doors to participation in the world open more widely as blind people are thought of as the individuals they are, and not according to stereotyped beliefs about them.

Blind persons benefit greatly when people with whom they interact use sound information about vision loss, free from conjecture. This is especially important for educators, employers, and others who decide what opportunities will be available to blind people. Family members of blind people likewise appreciate the social integration that this promotes.

The Complete Directory of People with Disabilities: A One-Stop Resource. 1997-98.

Leslie Mackenzie, publisher/editor; Laura Mars, consulting editor; Alexcia Fales and Nicholas Gottlieb, associate editors. Grey House Publishing, Pocket Knife Square, Lakeville, CT 06039. Toll-free number: 1-800-562-2139. Softcover, 832 pages, \$145; hardcover, 832 pages, \$170.

Now in its sixth edition, this directory is designed to be a one-stop resource for individuals, professionals, and organizations in providing access to the latest products and services for people with disabilities. It contains information about periodicals and books, assistive devices, independent living centers, employment and education programs, rehabilitation facilities, state and federal agencies, associations and support groups, camp and travel groups, clothing, conferences and shows, and legal information sources and referral agencies.

The first edition, published in 1991, had 5,000 entries. This edition has close to 8,000.

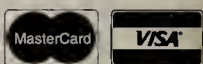
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AMERICAN REHABILITATION

Summer-
Autumn 1998

Personal Assistance Services Part 1 of 2



Personal Assistance Services

This issue of *American Rehabilitation* is the first of two devoted to the discussion of personal assistance services.

The need for personal assistance services is among the most actively debated issues in the rehabilitation and independent living arena. There is a wide variety of current research projects focusing on this concern, primarily research studies sponsored by the National Institute on Disability and Rehabilitation Research here in the Office of Special Education and Rehabilitative Services and by the Assistant Secretary for Planning and Evaluation in the Office of Disability, Aging, and Long-Term Care Policy at the Department of Health and Human Services.

Nursing and nursing aide services have been provided to individuals with significant physical disabilities since the beginning of organized society. In recent years, these services have been provided with increasing sophistication. The classic "Medical Model" paradigm applicable to the provision of nursing services presupposes that the individual with the physical disability is sick or that something is wrong with him/her and has needs for which to be cared. Caring services such as these have traditionally been provided in nursing homes and other institutions in order to permit a limited number of full-time staff to take care of a larger number of patients. The use of Visiting Nurses represented an expansion of these services enabling nurses and aides (under the direction of nurses) to be placed in the homes of people needing services.

The early challenges to the Medical Model paradigm began in 1959 with the advent of California's In-Home Support Services (IHSS) program, which not only placed providers in the homes of individuals receiving services but, most importantly, also required that providers follow the directions of the individual receiving services. The independence and confidence gained by individuals with significant disabilities receiving services through this consumer-directed approach was instrumental in developing the independent living movement in



Fredric K. Schroeder
*Commissioner,
Rehabilitation Services Administration*

California. Since then, consumer-directed personal assistance programs have developed in many states, each providing varying levels and types of services and serving varying disability populations.

The IHSS program in California has grown to provide services for 200,000 people with significant disabilities. A recent study of the IHSS program by A.E. Benjamin, Ph.D., et al., at the University of California at Los Angeles compared a professional agency model with a consumer-directed model and revealed that the consumer-directed model had a unit cost of approximately one-third of the agency model and that there was no difference in safety or unmet needs. According to the study, the consumer-directed model program provided the individual greater satisfaction with service quality, impact, and empowerment and better emotional, social, and physical well-being. The study results were consistent with a second study conducted in Virginia by Beatty et al.

The argument for home-based community personal assistance services was eloquently made by U.S. Attorney General Janet Reno on May 15 this year at the National Conference on Independent Living when she said:

"We believe that states have an obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs; and we have used the law to fight for this. Many

individuals with disabilities are being placed in nursing homes or other institutional settings even when they don't really need to be there.

"If the treating professionals conclude that the individual could live in the community with the right mix of support services, that is where they should be.

"But some states don't understand what I've been talking about and they refuse to make reasonable modifications in their policies that would allow this to happen. They deny people with disabilities from receiving community based services under already existing state programs."

A recent federal appeals court case, *Helen L. vs. DiDario*, established a legal framework for supporting community-based alternatives to the mandatory Medicaid provision of nursing home coverage. In this case, a number of nursing home residents brought suit against the Secretary of the Pennsylvania Department of Public Welfare (DPW), alleging that the department violated the Americans with Disabilities Act (ADA) by requiring that they receive required care services in a nursing home rather than in more integrated settings such as an individual's home. The United States District Court for the Eastern District of Pennsylvania granted summary judgment in favor of DPW. Following an appeal by one of the plaintiffs, however, the U.S. Court of Appeals for the Third Circuit held that the department violated ADA by requiring that the individual receive the required care services in the nursing home rather than through the attendant care program, for which she was qualified, in her own home.

Many of us are facing questions about how best to meet the long-term disability needs of aging parents. Many of the rest of us know healthy, capable individuals with significant physical, sensory, cognitive, or mental disabilities who need some form of personal assistance services on a daily or weekly basis in order to live independently. I believe that individuals with significant disabilities need personal assistance services not only to survive, but also to achieve their life potential. **AR**

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The weakest ink is better than the strongest memory.

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Independence Care System: Managed Care for People with Disabilities

The Paraprofessional Healthcare Institute is a nonprofit organization and a sponsor of ICS, based in the South Bronx, that interlinks a network of worker-owned healthcare providers specializing in paraprofessional services.

The mission of PHI is to:

- *provide high-quality healthcare to clients who are elderly, chronically ill and disabled, and*
- *create decent jobs for low-income women, with an emphasis on those who are unemployed or transitioning from welfare to work.*

*Mary Ann Wilner, Ph.D.
Ann Wyatt, CSW, NHA*

Introduction

The healthcare system in general, and managed care programs in particular, often view people with disabilities as "problem consumers" who are not easily treated due to their multiple, interrelated conditions and impairments. Independence Care System (ICS) will be the first managed long-term care program in New York State designed expressly to meet the needs of people with disabilities. The other existing and planned programs in New York state focus on the elderly. The goal of Independence Care System is to enable people with disabilities to remain at home or in the least restrictive setting possible by integrating the full range of primary care, acute care, and home and community-based services in a comprehensive, flexible manner.

Through ICS we will demonstrate a managed long-term care approach that builds on NYC's existing system of healthcare and social service providers in developing a specialized program for each of the ICS members and highlights the way home care paraprofessionals can play a vital role in supporting people with chronic illnesses to live independently at home and in their communities.

ICS is expected to begin in January 1999. Our program plans to enroll 800 participants in the first 3 years of operation and 2,000 within 8 years. Two hundred people are projected for enrollment in the first year and 300 people per year in the following years.

Target Population

ICS will serve people with significant physical disability or chronic illness who are eligible for nursing home level of care and Medicaid benefits. This includes primarily younger adults with significant disabilities, such as quadriplegia, paraplegia, poliomyelitis, muscular dystrophy, and multiple sclerosis. ICS will also serve a relatively small number of older people who wish to receive consumer-directed personal care services.

People with disabilities want to remain at home for as long as possible, to be supported by family, friends, and familiar service providers. Individuals with severe disability are exclusively neither acutely nor chronically ill. Instead, their conditions tend to be long-term, often degenerative, with episodic flareups that may have an uncertain prognosis. Their concern is much less with "curing" their illness than with managing their illness with maximum dignity and comfort. As a result, the clients require care that recognizes and responds to their very particular needs—care that is delivered in a co-

Dr. Wilner is Director of Health Policy, Paraprofessional Healthcare Institute, and works in collaboration with consumer, worker, and high quality provider agencies to educate state and federal policymakers about "the labor impact of healthcare policy." She also develops advanced educational programs for the home health aides in the Cooperative network. Ms. Wyatt is Director of Care Management, Independence Care System, and has been instrumental in designing Independence Care System.

ordinated, "seamless" manner and blends both medical and support services. They also require continuity of care so that both client and family can be supported emotionally and psychologically—not just medically—over extended periods of time.

Two of the most critical services for living at home or in the community—primary care and paraprofessional home care—are not easily tailored to meet individual needs. The typical client with disabilities either has no accessible primary care physician or, at best, relies on a physician who has little knowledge about chronic illnesses and severe disabilities. The result is discontinuous and, at times, even conflicting medical advice as well as a general failure to monitor closely the progress of chronic conditions, low-level illnesses such as colds or infections, and changes in mental status. Unattended, these conditions often lead to dangerous complications ranging from pneumonia to substance abuse. Too often, the results are unscheduled hospital and emergency room visits that are not only very costly but are also truly avoidable. Physicians are also often unaware of the importance of decent nutrition, safe surroundings, and adequate exercise for patients with disabilities.

Paraprofessional home care is widely regarded by many disabled individuals as a primary support for independent living. Home care aides are the immediate link between client/family care givers and professional service providers, particularly in terms of daily support for self-care and prevention programs, early detection of problems, and changes in physical condition. Yet within the formal service system, the paraprofessional is often perceived as a "glorified domestic servant" and relegated to second-class status. Therefore, paraprofessionals are rarely respected, trained, or communicated with in a way that recognizes their value to the health-care team. ICS's relationship with Cooperative Home Care Associates, a home healthcare agency that values frontline workers, represents a school of thought about paraprofessional home

care that directly connects investment in the frontline worker with a higher quality of care and self-direction for its clients. This unique role for paraprofessionals differentiates Independence Care System from the few other managed care demonstrations for individuals with disabilities.

Organizational Structure

Cooperative Home Care Associates (CHCA) is a 14-year-old worker-owned home healthcare agency employing more than 400 African-American and Latina women as home care aides in the Bronx and Harlem sections of New York City. CHCA and its affiliated worker-owned home healthcare cooperatives in Boston, Philadelphia, and Waterbury, Connecticut, have become widely recognized as a model for pro-

Paraprofessional home care is widely regarded by many disabled individuals as a primary support for independent living.

viding both high quality paraprofessional home care jobs and high quality services to its acutely and chronically ill, disabled, and elderly clients. CHCA received the 1992 "Business Enterprise Award" from the Business Enterprise Trust for social responsibility in business, the 1993 "Brookdale Award for Best Practice in Human Resources and Aging" from the Brookdale Center on Aging and the American Society on Aging, the "1997 Corporate Conscience Award" for employee relations from The Council on Economic Priorities, the 1998 "Gloria Award" from the Ms. Foundation, and the 1998 "Advocacy

Award" from the Home Care Association of New York State.

Together with its nonprofit affiliate, The Paraprofessional Health Care Institute (PHI), CHCA sponsored the development of Independence Care System. In 1997, New York State passed legislation enabling the Institute and Cooperative Home Care to operate ICS as a managed long-term care demonstration program.

ICS will be a nonprofit organization. Its board of directors will consist of consumers, major stakeholders in service delivery for this population, the Paraprofessional Health Care Institute, Cooperative Home Care Associates, Visiting Nurse Service of New York, and Concepts of Independence (a fiscal agent that receives Medicaid funds and pays wages and benefits for paraprofessionals hired, trained, supervised, and dismissed by consumers). A consumer advisory council has been established consisting of representatives of advocacy organizations. The program will have a full-time ombudsperson available to all ICS members.

ICS Program Description

Independence Care's program has four key elements:

1. *Consumer Participation.* We are building a new framework for balancing provider and consumer perspectives that incorporates substantial consumer participation in governance as well as a role for consumers in care planning and care management. Encouraging client self-direction recognizes the client's and family's right to maximum autonomy while still obtaining support from the formal service system.

2. *Emphasis on Home and Community-Based Care.* We emphasize a "consumer's eye view" of the service network, focusing on home care and community-based care. Primary care, home care, and other community-based services will substitute for far more expensive inpatient and institutional care. Within the provision of home care, the model particularly highlights paraprofessional services.



3. *Full Range of Services.* We will offer the full range of supports and services that consumers value. This includes: an option of consumer-directed paraprofessional care; a service of specialized and highly trained home care aides; respite care for families; consumer peer training; care management; and social day care. These services will be widely available to consumers who will be afforded maximum flexibility in their use.

4. *A Specialized Integrated Network.* We will coordinate care over time, with multiple providers, and across primary, acute, and long-term care settings. The process of care will appear "seamless," so that information obtained from the consumer is shared and used by vari-

ous providers (and is not repeatedly requested from the client)—reducing the use of specialists and clinics, and eliminating duplicative tests, or worse, countervailing medications.

ICS will initially offer a benefit plan which will include care management, home healthcare, personal care, adult day healthcare, durable medical equipment, transportation, prescription and non-prescription drugs, podiatry, dentistry, optometry, audiology, home delivered meals, social day care, respiratory therapy, social and environmental support, rehabilitation services, and nursing home care.

Inpatient and outpatient hospital services, physician services, and several other areas will initially be ex-

cluded from the Medicaid capitation arrangement; however, care will be coordinated by ICS. Providers will bill Medicare directly for Medicare covered services. This plan will become fully capitated, including all benefits, when an appropriate waiver is obtained by the State Department of Health from the Federal Health Care Financing Administration. We expect a waiver to be obtained by the year 2002.

ICS will be built around care management teams. Upon enrollment, each member will be assigned to a physician, a nurse practitioner, a nurse, and a social worker. Home care aides and other providers will also be members of the team. Different team members will assume responsibility for care coordination, depending on the needs of the client. Each nurse practitioner will provide support for approximately 50 clients; nurses and social workers will each have caseloads of about 25. Caseloads may be smaller or larger, depending on client need. Care planning, care management, and conflict resolution will be the overall responsibility of the care management team, under the leadership of the care coordinator.

The ICS service network will have a broad array of options and will be diverse in specialty and geographic capabilities. ICS members will be able to retain their physicians and home care aides if they wish, as long as the provider agrees to use our standards and protocols. This network will continuously work toward integrating its activities through interdisciplinary training, information systems, and practice guidelines.

The ultimate success of the program will depend in large part upon our ability to establish a sense of community among our caregivers and our client members. With this sense of community will come the trust, loyalty, and mutual support that provide the basis for a successful long-term relationship. This is the philosophy that has driven the development of Cooperative Home Care Associates and The Paraprofessional Health Care Institute for the last 14 years.

Essential Role of Paraprofessionals in ICS

Home health aides and personal care aides are more important in a cost constrained environment than under a fee for service system. By being an integral member of a consistent team responsible for working with the consumer, the aide becomes a coach, an observer, and a partner in care. To prepare each of them to assume the added responsibilities of working in the ICS program as a specialized aide, our CHCA aides will receive additional training, which will focus on deepening their understanding of the rights and autonomy of consumers who wish to direct their own care; sharpening their skills at communicating and negotiating with consumers and team members; and broadening their perspective so they can appreciate the world as experienced by people with disabilities. They will also learn specific skill competencies associated with clients with selected types of disabilities.

Our specialized training program will expand beyond the 4-week training currently required of every CHCA aide. In our cooperatives we have sought to replace the typical "low-investment," "temporary personnel" approach with a strategy of "high investment" in front-line employees—emphasizing careful recruitment, decent wages and benefits, full-time work, extensive training, counseling, and support. Our worker-ownership model further reinforces the enterprise, both as a paraprofessional-oriented business and as a community of coworkers. Each employee has the opportunity to own a single share of the company; annual dividends paid to worker-owners in recent years have ranged between \$250 and \$600.

Our direct experience within our network of worker owned home care agencies demonstrates that frontline workers need the following kinds of supports in order to ensure both a decent job and the delivery of high quality care:

- **Adequate Compensation.** Frontline workers need a living wage with adequate pay and benefits. Yet, most health paraprofessionals are women

Peer support is as important as supervisory support.

who are working but poor—in 1993, more than 600,000 direct-care workers lived below the poverty line. Paraprofessionals are asked to provide high quality health and personal care yet they are often not provided health insurance.

- **Stability.** To have a job that is financially secure, aides need guaranteed hours of work. Home care service agencies that typically offer only part-time jobs have found that offering guaranteed hours to a portion of their workforce dramatically reduced turnover.

- **Selection.** Retention of high quality workers requires careful selection of workers who are mature, sensitive, and interested in caregiving work. Careful screening can save agencies both time and dollars by reducing expensive turnover.

- **Sufficient Training.** Organizations that believe in the capacity for employee growth must provide opportunities for them to grow. CHCA in the South Bronx provides 4 weeks of training—twice the federal requirement—and emphasizes communication, problem solving, psychosocial development,


The ultimate success of the program will depend in large part upon our ability to establish a sense of community among our caregivers and our client members.

and job readiness, in addition to all the clinical skills required by regulation. The training team includes former home health aides who have advanced to associate instructors—a powerful role model for new trainees.

- **Supervision.** Paraprofessionals need good supervision to manage the complexity of cases they are now seeing in home health and nursing facilities. Yet, few nurses or coordinators have been trained in management and supervision. Our network's Home Care Associates of Philadelphia has begun a coaching program that provides supportive supervision to aides.

- **Support.** Peer support is as important as supervisory support. Some nursing homes are starting to sponsor "CNA support groups" for aides who come together to exchange client information and caring techniques, support one another, practice communicating with peers and supervisors, and have a safe place to grieve the loss of residents who have died. At CHCA, a former home health aide who is now an associate instructor conducts a "Rap Session" that functions as a peer-oriented support group for new aides.

- **Upgrading and Promotion.** Although many paraprofessionals love their one-on-one work and have no desire to become trainers, nurses, or supervisors, they still want the respect and pay increases that seniority deserves. CHCA has promoted a small core of aides to higher level positions such as associate instructors. Several are now in part-time administrative positions assisting with competency training and office work when they are not in clients' homes. One home health aide has become a registered nurse and another a social worker. We are also offering a number of college courses—delivered at the workplace—so that paraprofessionals can expand their knowledge and advance their education.

Aides selected to work with consumers in the new ICS program will be well-prepared to assume their new responsibilities. They in turn will become teachers and mentors for new aides who enter the ICS program as membership enrollment increases. 

Home Care Benefits for Persons with Disabilities

Nearly 49 million people over age 5 (19.4%) have a disability of some type. Of these, 24.1 million have a severe disability. Of the noninstitutional population over age 5, 4 percent (9.2 million people) need personal assistance with one or more activities of daily living (ADL's), such as bathing and dressing, or an instrumental ADL, such as shopping or cooking. One percent (2.5 million) have a developmental disability or mental retardation. One person in seven (37.7 million) has an activity limitation, and of these 12 million are unable to perform a major activity, whether it be work, school, or play, depending on age. The prevalence of most physical disabilities increases with age, while the prevalence of mental retardation/developmental disabilities (MR/DD) is highest among those under age 18.

(Krauss, Stoddard, & Gilmartin, 1996)

Walter Leutz, Ph.D.

Persons with disabilities (PWD's) of all types and all ages usually prefer to live at home rather than in institutional settings; and policy-makers, professionals, and families tend to concur. The impacts of chronic and disabling conditions can be ameliorated by home- and community-based (HCB) services such as personal care, homemaking and chores, transportation, and day center care. Under current benefit and service systems, HCB care is differentiated from "skilled" or "home health" care. The latter is covered under medical insurance—typically for a period of recovery after an acute condition, but also for ongoing care that requires supervision of a physician or involvement of a nurse or therapist (Bishop & Skwara, 1993). The shortcomings in current United States HCB service and benefit systems have led service users and policymakers alike to consider radical changes in those systems, including simply giving cash to users to buy services on the market. Before examining cash alternatives, current shortcomings should be understood.

Institutional spending bias: Despite preferences for home care, the bulk of public long-term care (LTC) funds are spent on institutional care. In 1994, 81 percent of Medicaid's \$45.6 billion in LTC spending was on institutional care (61% on regular nursing facilities and 20% on intermediate care facilities for persons with mental retardation). Of the 19 percent spent on HCB care, \$3.9 billion went to HCB waiver services, \$3.0 billion to personal care, and \$1.6 billion to home health (Graves and Bectel, 1996). Other public funders of HCB services don't make up for the

disparity (AARP, 1995; Alecxih, Corea, & Kennell, 1995; Pepper Commission, 1990; Wiener & Sullivan, 1995). For example, in 1993, other state and federal spending on HCB services for elders amounted only to \$2.1 billion (Committee on Ways and Means, 1996). Medicare spending on home health has been rising rapidly, from \$2.8 billion in 1988 to \$15.7 billion in 1995 (Mauser, 1997), and most of the new spending has been on home health aides for long-term patients (Welch, Wennberg, & Welch, 1996). However, Medicare is an expensive way to deliver HCB services, access varies tremendously geographically, and the 1997 Balanced Budget Act provisions are intended to rein in growth through both managed care and new incentives on home health agencies themselves. Private insurance systems do very little to fill the gaps in home care benefits, and disability insurance is designed to replace wages not pay for services. The number of LTC insurance policies sold is rising rapidly, but policies are affordable only to the well-off (Crown, Capitman, & Leutz, 1992; Rivlin & Wiener, 1988). This may explain insurers' expectations that half of the policies they sell will lapse in 5 years and that 65 percent will lapse in 10 years (GAO, 1993).

Services not benefits: The multiplicity of small HCB care programs—often aimed at particular groups of PWD's—makes for a fragmented, underfunded, and confusing patchwork of services. And aside from Medicaid personal care, care is offered through service programs rather than a benefit system. A

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"benefit" implies access to a set of covered services on an equitable basis for a defined group of eligible individuals. Benefits need not be entitlements in the sense that no limits are put on access (e.g., gatekeepers, discrete resource limits), but true benefits should be adequate to address the needs of all eligibles equitably. In contrast, a service program can establish waiting lists and make no pretense of meeting needs. Although some states have done better than others both to increase resources for home care and to strengthen the service delivery infrastructure (Leutz et al., 1992), eligibility, choice, and coordination problems are widespread.

Gaps in eligibility: Because HCB services are optional state benefits under Medicaid and because there are numerous smaller HCB service programs aimed at particular groups of PWD's, there are differences both across and within states in which groups of PWD's receive public support, how much they receive, and under what conditions (Liu, Hanson, & Coughlin, 1995; Leutz et al., 1992). The result is a system of "haves" and "have nots," with some families and PWD's stuck in "no care zones" in which their age, disability status, location, or income exclude them from assistance which they formerly had or which others with no greater apparent need seem to enjoy (Kassner & Martin, 1996; Litvak & Kennedy, 1991).

Confusing choices: "Choice" has become an anthem for critics of HCB care systems—and with good reason. Fragmented funding and administration leave new users struggling to understand their options with confusing choices among programs that offer only

partial solutions (Baldwin & Twigg, 1991), while care management tools administered to those who find their way seldom ask users and carers how they see needs or what help they want (Leutz & Sciegaj, 1997). Creating single entry points to benefits and then listening to what users want are first order choice priorities which few states have addressed adequately (Leutz, et al., 1992).

Poor coordination with related service systems: For PWD's of all ages, HCB systems overlap with related systems of benefits and care, particularly health systems (Leutz, 1994; Leutz et al., 1995; Schlesinger & Mechanic, 1993; Tanenbaum & Hurley, 1995; Williams & Weisert, 1994). Coordinating with these systems is an opportunity to improve quality and efficiency, but the opportunity too often is missed in the face of time, cost, conceptual, turf, and logistical barriers to integration (Leutz, forthcoming). Emerging managed care approaches that integrate the finance and delivery of acute and LTC move eligibility, choice, and coordination problems into the interior of private health-care systems. The hope is for better care and enriched benefits, but there is also the possibility that tighter management will reduce HCB benefits by imposing tighter eligibility definitions and closer management of utilization (Schlenker, Shaughnessy, & Hittle, 1995).

Conflict with income support programs: Two key provisions in U.S. income support systems for PWD's affect HCB care. First, unlike some European countries (Evers, 1995), disability and retirement benefits are not available in the United States on the basis of providing family care to a PWD. Second, health and LTC benefits that are linked to Supplemental Security Income (SSI) are lost when beneficiaries' work puts them over income limits. This is one reason that PWD's have low incomes (Davis & O'Brien, 1996), and the fact must be considered in designing coinsurance for HCB care.

Few members of the general public understand these deficiencies in HCB benefits until they need them. Most people expect that their health insurance or the broader "welfare state" will

protect them. But policy experts know that the earth is still flat in the world of LTC. When you get to where you need it, you may fall off into the abyss—along with your money, your family, and your dignity.

In the early 1990's, policymakers considered filling gaps in HCB care benefits nationwide through new service and income entitlements for PWD's and their families (Clinton, 1993; Rowland, 1989; Pepper Commission, 1990). Models and momentum for some proposals were built on concurrent European initiatives, some of which went forward (Evers, 1995). Just a few years later in the United States, these proposals seem not only remote but discredited. The very notion of universalistic social welfare programs is in retreat in the face of attacks from the top by those who believe that private markets solve problems better than government and from the bottom by libertarian ideas fueled by frustrations with government regulation and overbearing professionals. The transformation of "clients" and "patients" who "need care" into "consumers" seeking "choice" in social welfare "markets" is symbolic of the change in thinking, which again is most clearly analyzed in Europe (Barnes & Walker, 1996; Taylor-Gooby, 1994).

The HCB benefit model that is benefiting most from these new dynamics is to simply give PWD's cash to buy what they want to meet their perceived needs. As discussed below, cash systems can vary regarding how the payment level is set, what cash can buy, what administrative supports are offered, and how closely user status is monitored. A large "cash and counseling" demonstration is now underway in several states (NCOA, 1997). As all states gain flexibility in the use of disability care funding streams through block grants and other mechanisms, the opportunity to create cash benefits will increase.

In Section II, I critically review cash benefit approaches and suggest safeguards and options that should be included. Although there are strong reasons to give service users more

Few members of the general public understand these deficiencies in HCB benefits until they need them.

control—including the option of taking cash—we must be careful to recognize and respond to cash's ideological and practical pitfalls. Market rhetoric has great appeal, but there are dangers in turning the care for PWD's into commodities and trusting that the market will respond. Market failures, competitive abuses, and exploitation of carers are possibilities. Also, cash will not work equally well for all PWD's, which means that public administrative savings may not be realized.

In Section III, I offer a companion approach to strengthening home care benefits in light of changing political and ideological realities. I propose that we make conscious and material efforts to help communities promote and develop services. This may seem like an idealistic and nostalgic swim against commercial tides in human services, and much work needs to be done on defining community and how to support it. But given the alternatives, the effort seems worthwhile.

In Section IV, I summarize the recommendations in light of current home care policies and programs. The state of our political economy precludes a proposal for extensive expansions of benefits, but the analysis and recommendations are relevant to the narrow spaces where home care benefits currently exist and point to ways that those spaces could be extended to round out coverage in the flat world of LTC.

Cash for Home Care: Avoiding the Trap of Consumerism

This section examines the promises and pitfalls of giving PWD's cash to buy care. I will argue that a free market application of the consumerist model is unlikely to yield home care benefits that many people either want or need without extensive regulations and supports. Moreover, the market offers what for many may be hollow answers: purchased services rather than places in society; commodities rather than communities. Much of the enthusiasm for cash and counseling comes from European models (Laing, 1993; Keiger & Stone, 1994), but European experience

is not extensive, and many observers have concerns. At least six areas of concern stand out.

Does favoring choice require throwing out professionals? Given the strong currency of the choice concept (Social Services Inspectorate, 1995; Tyne, 1994; Vladeck, 1995), it is important to examine what choice means in home care and when giving cash and a market choice makes sense. Long-term home care often presents circumstances in which user choice and control are important, for example, regarding "who and how" when service is intimate, personal; regarding place and time; and regarding long-term arrangements. This describes the circumstances of working-age persons with physical disabilities (Batavia, DeJong, & McKnew, 1991). Being able to hire, train, and supervise an aide to provide this care is the classic case for giving cash to PWD's.

However, as one of my reviewers pointed out, "Choice has an ideological 'patina' that makes choice seem good, in and of itself, regardless of unintended consequences." Letting consumers shop around with cash may not be the appropriate answer in crisis situations or in cases where care is skilled. "Making choices implies judging and action, when what we may want is to have our needs met. Having to make a choice may be unwelcome if it causes delay or uncertainty. . . . Choice is experienced as risk" (Barnes & Prior, 1996:5). Thus, cash and the free choice it promises are valuable to address some care needs but not others.

What will the market supply? Market enthusiasts assume that private providers will respond to newly empowered consumers with choices for innovative home care products. There is no assurance that this will happen,

particularly in small markets, or that providers will be experienced, honest, or qualified. Even where there are options, consumers need experience and skill in making choices, good information about quality and the terms of purchase, and the funds to afford the choices (Pijl, 1994). Individual consumers may not be able to negotiate prices and terms of service that are as favorable as the state's bulk purchasing power. There is also the potential that large and well-financed home care firms will drive out smaller local firms through predatory pricing, hard sell advertising, hiring away staff, and other well-tested practices of would-be monopolists. There is nothing in the nature of "free" markets that gives confidence that unsatisfactory results will be avoided without regulation and other supports (Kuttner, 1997).

Will cash mean cuts in care? If cash attracts more users to the system, and if total spending is not increased, it follows that the amount of cash given to each user must be less than would have been spent on individual care plans for agency services. Cash advocates' contentions that users will find and buy services more economically also supports the idea of lower spending per user. What level is adequate is not clear: The new German home care plan pays half of the formal care plan costs in cash (Evers, 1994). Early experience is that more than 80 percent of users take it. However, benefits are not income-tested, so most (but clearly not all) people can afford to supplement. Supplementation will be all but impossible for Medicaid users under U.S. cash and counseling models. A related concern is whether the cash is seen as the end of responsibilities for public programs, or whether other supportive services that are difficult to buy on the market will be available. Inadequate cash grants without supportive services could increase isolation and risk.

What infrastructure supports will be needed? Virtually all European systems require a payment system and an assessment/reassessment to determine the level of payment. Most systems add (1) oversight to ensure funds are spent

Much of the enthusiasm for cash and counseling comes from European models . . .

on services (unless vouchers are used), (2) some monitoring of quality, satisfaction, and outcomes, and (3) a scheme to help users maintain the records and controls needed to comply with tax, reporting, and other system requirements. Additionally, regulatory and perhaps legislative actions are required to clarify various legal issues (e.g., how payments affect user and carer eligibility for other service and entitlement programs, and whether minimum wage laws apply and how they will be enforced). Finally, current case management systems will need to be maintained for those who do not choose cash, and new case management systems will be needed to assess and monitor those who do, including more extensive support for those who are not able to manage the cash on their own. For example, in the United States, PWD's who employ their own aides must maintain Federal Insurance Contribution Act (FICA) tax recording. Thus, if policymakers reduce administrative expenditures under a cash grant system, we should expect confusion and inefficiency at best and scandal and exploitation at worst (Leat & Ungerson, 1994).

Will family members and other carers be treated fairly? Giving PWD's cash to buy care introduces potential conflicts between family carers and PWD's, including whether users or family members control the cash and whether cash is used to support family carers (e.g., respite). By all accounts, family carers provide at least two-thirds of the help that PWD's receive (Fischer & Eustis, 1994; Kahana, Biegel, & Wykle, 1994; Tennstedt, Crawford, & McKinlay, 1993; Twigg & Atkin, 1994). The large majority of family carers are women, who may already have other family obligations and who often make career sacrifices to provide care. Some feminists oppose encouraging family care (as would be the case if cash were allowed to pay family members), but others value women's caring nature, accept that caring opportunities/obligations will present themselves at various points in peoples' lives, and focus on how fairly to support caring with

Empowerment of one person should not result in exploitation of another.

adequate programs (Baldwin & Twigg, 1991; Evers, 1994; Johansson & Sundstrom, 1994; Lingsom, 1994). They favor an "emancipation policy" that includes fair wages and benefits, limits on amounts of informal care, and various other supports: facilities for day care, holiday leave, professional support, skills training, insurance, buildup of pension rights, and a network of informal carers (Pijl, 1994).

Without these types of specific guarantees, cash to family carers can continue if not expand exploitation of women. For example, one pay for care experiment in Canada found long hours, high burnout, wages at less than half the minimum, women being encouraged to quit jobs to provide care, and refusal by public sector to add services if there was a paid informal carer. The evaluation found that pay for care often created a cross between wages and welfare with work up to the welfare limit and wage cuts thereafter (Stryckman & Nahmiash, 1994).

Conflicts with nonfamily carers around hours, wages, and other conditions of work may be even sharper (Ungerson, 1994). If the government leaves these as gray areas, and workers leave agencies to become independent contractors, home care workers could lose even the few protections and benefits they now receive from employing agencies. A new type of domestic service could be created, using various categories of vulnerable people (e.g., welfare mothers, immigrants who will work for small wages and housing). These issues have always been tied up with class, gender, and race.

Should caring be a commodity? Offering cash instead of services shifts power and choice to consumers but it also makes them responsible. If that's all there is, it disconnects society and professionals from results. The over-

bearing professional bows out in deference to the theoretically responsive market. But if theory falls short of reality, who will we blame: economic theory or the consumer who was not a savvy shopper?

In addition to changing the relationship between the public and the PWD, commodification of family support responsibilities could upset delicate balances in these caring relationships. The idea of offering "incentives" to caregivers is misguided, since it would be aimed at the minority who do not meet their caregiving responsibilities voluntarily. A Dutch study that offered cash for caring found that informal carers saw the gesture as more important than the amount of reward. "A bad relationship between a recipient and a caregiver cannot be compensated by money... people feel a moral obligation to care." Volunteers feel similarly as only a minority would like higher compensation (Pijl, Mandmaker, Daal, & Schoonman, 1994:154). Similarly, a survey of New York City caregivers found that they valued financial incentives much less than service and emotional supports. The most desirable supports were homemaker (26%), medical care (25%), social center (12%), monthly check (10%), and general services (9%). Overall, 80 percent picked a service first, while 20 percent picked financial support (Horowitz & Shindelman, 1983). The authors were not surprised with the findings, citing earlier studies that found that the pressure with caregiving is more emotional and social than financial. Similar preferences for services over cash have been reported in Sweden (Johansson & Sundstrom, 1994).

In summary, all six questions point to the need for a substantial amount of intervention and oversight in the private home care market if users are given cash as an alternative to case-managed benefits. Features include assessment and reassessment to set the level of cash payments, support for users in hiring and keeping records, monitoring of the adequacy of the level of payment based on what can be purchased, oversight of home care firms'

competitive and sales practices, employment conditions for hired carers, and support to help families and users work out conflicts about the use of cash. Furthermore, the option of using traditional case-managed access to benefits will need to be maintained alongside the new system.

Free market advocates may argue that all this is unnecessary and discredited regulation of agreements that individuals can and should make on their own. The potential for abuse and neglect in LTC is so strong, however, that it is almost inevitable that payers will be required to oversee the use of public funds. There is no reason to think that such oversight will be any more successful in avoiding scandal and abuse than oversight of provider agencies, but it is likely to be required nonetheless.

Process: Community Action and Social Reciprocity

As an alternative to relying on consumerism and markets to define home care benefits, I propose a more proactive community development strategy. The United States is an extremely individualistic society, but we also have a history of collective community action on the local, state, and national levels. Community action relies on the voluntary participation of citizens; it operates primarily through democratic and open processes; and it is driven primarily by goals of collective betterment rather than individual enrichment.

The concept of community used herein is broad. Examples of community include participation in groups for self-help, advocacy, service, and advice giving. Community groups are sponsored by government, religious institutions, civic organizations, and by or on behalf of sectors of society (e.g., women, youth, elders). A very common form is the nonprofit corporation to collect and distribute money (foundations) or to provide services (innumerable voluntary agencies), but the formation of public programs in response to community action also may be seen as products of community.

Other examples include community coalitions, special authorities, tenants and neighborhood organizations, and community action agencies. There are differences in the processes and powers of these various forms, and the options will differ for each community in terms of its capabilities and issue in terms of the forums available, but all are expressions of community.

This all may sound like 1960's rhetoric, and I acknowledge that advocating community action is swimming against the individualistic and market tides, particularly when it seeks support from public funds. Despite a history of community activism and volunteerism in the United States, we don't have nearly the sense of solidarity that still characterizes many European states or even Canada (Buxbaum, 1992; Clark, 1991). Even when it produces results, community action does not mean that conflicts among groups for resources will go away or that unsatisfactory solutions will always be avoided. There are "community failures" just as there are "market failures." Yet the results of successful community action are undeniable, particularly in the field of services for PWD's. The achievements of the disability rights advocates and active parents in deinstitutionalization and educational integration are testimony to the power of community action, as are the innumerable voluntary nonprofit agencies that provide health, educational, vocational, residential, and human services for PWD's.

Beyond the material results of community action, it can be a vehicle for legitimization for disability issues and integration of PWD's into the community. Isolation from community life is a common problem cited by PWD's and their families (Cooley, 1992; Hirst & Baldwin, 1994). Becoming active in formulating service strategies, agencies, and policies as well as participating in self-help and mutual-aid activities not only breaks down isolation, but also contributes to the community itself.

A foundation for the process can be found in the principle of mutual obligation or reciprocity, through which PWD's and families are acknowledged

to be giving back to the community in exchange for the support they receive. Recognizing these reciprocal relationships helps to maintain community in the face of a market society which "emphasizes economic values and individualization, which breaks down communities and produces alienation" (Moroney, 1986:173). Also avoided is the residual approach to welfare: "We"—who are independent—give to support "them"—who can't support themselves. This puts the process of developing and delivering home care benefits on the basis of what communities can do together rather than the notion of what individuals are "entitled" to from the community or on the notion of what they can buy on the market. The goal of community integration suggests several process features for developing home care benefits for PWD's (Leutz, 1994).

First, communities (as embodied by PWD's, carers, concerned professionals and providers, and other supporters) can develop and encourage new services. Depending on political and community realities, these might range from sponsorship by public sector agencies—if funding can be obtained to direct services provided by nonprofits—to volunteer help lines and carer support groups. Well organized and informed communities can even adopt new taxes to support HCB care, as did one Ohio county in 1992 (Logan & Applebaum, 1995). Communities can also set expectations for user and community involvement in traditional nonprofit and for-profit providers. If communities become more active in working with all kinds of providers, heavy-handed external regulations may be less necessary.

Second, these community initiatives need resources. Medicaid should allow purchase of these services through home care benefits, rather than restricting coverage to services that meet usual licensure, quality, and reporting requirements. Direct support for organizing and infrastructure is also needed. For example, Canada launched the New Horizon's Program in 1972 to encourage older people to use their own skills and talents to combat social iso-

lation and to address needs. This nationwide community organizing effort provides federal technical assistance and local grants for space and other direct costs but not for professional staff. The initial focus of the program, which awards 18-month grants with the possibility for one followup of 18 months, was on senior centers, but in 1982 initiative moved to community services, self-help, education, and self-advocacy. After 10 years, 90 percent of the 20,000 projects funded were still active (Novak, 1987). By the late 1980's, more than \$200 million had been given to 32,000 programs (Clark, 1991).

Third, participation of disabled people in home care benefit design must be real rather than window-dressing. This not only may mean seats on policy and governing boards, but also developing supportive forums where service users and carers can meet to talk among themselves to formulate positions that can be taken to larger bodies. This will require support for the process and sensitivity to special needs, including thinking through how to gain fair representation of disabled people (Bewley & Glendenning, 1994), setting meetings at times and places that are convenient, offering help with transportation and communications, and putting in the staff and other resources that are needed. The Interagency Coordinating Council form used to oversee Title 5 education funds for early intervention is a good U.S. example. It includes hiring parents of disabled children in designated staff positions in state government and parents and providers meeting publicly and regularly to consider and advise on policy and program matters.

Fourth, the process should ensure that all interests are represented fairly. Consumerism is an individualist notion—maximizing one's own needs and satisfaction without reference to others with similar needs. Care needs to be taken that participatory processes are inclusive, since they can go wrong too, through a tyranny of majority or domination by the articulate middle class, for example (Barton, 1993). Empowerment of one person should not result in

exploitation of another (Barnes & Walker, 1996). Coalitions among different groups of PWD's may foster more coherent disability policy rather than special treatment for the most successful groups.

Fifth, professionals and policymakers must accept and support changes in procedures, power relationships, status, and security. This will be no mean feat, since professionals have great investment and experience in running the system and will be loathe to cede territory (Schorr, 1992). Furthermore, service users are conditioned to deferring to professionals or, at least, telling them what they seem to want to hear (Clark, Dyer, & Hartman, 1996; Cooley, 1992). To facilitate change, professionals and policymakers should start from the proposition that "authority deriving from professional knowledge is balanced by authority deriving from the experiential knowledge of the user..." (Barnes, et al., 1996). Empowerment of the consumer does not remove the responsibilities of those who produce services; the responsibility to learn and change remains.

Sixth, in designing home care benefits, communities should consider how needs, resources, and preferences may vary across groups and individuals. People become disabled at different points in life (e.g., birth, adulthood, and old age); this affects what a person has been able to do before he/she became disabled, including being prepared financially for the costs of disability. On another level, impairments that foster disabilities are of different types, intensities, and trajectories. The impact of a short-term disability from which a person recovers is different from a short-term degenerative disability which is in turn different from a long-term stable disability.

Finally, the types and levels of support change with the life cycles of both carers and PWD's; the community should be sensitive to these changes, valuing the help that is given and providing help when it is needed (Gerry & Mirsky, 1992). The life cycle concept helps us untangle the relative stresses and burdens of different patterns of

caring and to think about how home care benefits should relate to family carers. For example, for the first year or two of life, a child with a physical impairment causing lower body paralysis may require the same care as a typically developing infant, and society considers it normal that parents (particularly mothers) provide this care as a matter of course. As the two children age, however, the former's care needs will increase—eventually to the point where he will be too heavy for the mother to lift and where (if he is male) sexual taboos may interfere with her ability to help with toileting, dressing, and bathing (Litwak, Jessop, & Moulton, 1994). And the teen turning 20 will want a life independent of his parents. These are very different family care relationships than those of a wife's caring for her husband of 50 years. Similarly, a spouse/carer of retirement age is in a different life cycle point than a daughter/carer of working age and should be able to get different help through LTC benefits.

Thus, in general, policy and programs should recognize that both the carer and disabled person have different needs for independence, work, income, recreation, pensions, pay for care, etc., at different points in their lives. If we ask people what they want, many would indicate that modest expenditures (in cash grants or service supports) would be sufficient. One of the earliest but most important studies of home care preferences found that families and users asked for less than professionals thought they should have (Sager, 1980). Different rationales apply to PWD's of different ages, types and severity of disability, different family situations, and different life cycle stages of carers. Purposes might include compensating for the costs of disability, supporting care, providing income, or to compensate carers. Current assessment and care planning approaches are not equipped to respond to diverse or idiosyncratic preferences. It will take leadership from communities and policymakers to develop the basis for this kind of response, as well as the training of resource allo-

cators to help service users to think through and choose options.

In summary, I recognize that many will be skeptical of both the feasibility of supporting community initiatives and user empowerment, particularly in a time when individualistic and market oriented solutions are in the ascendancy. For example, in comparing long-term care in the United States and in Canada, Clark (1991) observed: "Strait jacketed by narcissistic individualism, [Americans] are unable to engage in any meaningful public dialogue on what the goals of society should be and the appropriate means for achieving them. . . . We substitute economic incentives and cost-cutting procedures for real social dialogue in the vain hope that these will solve what is at heart a crisis of shared values and principles. . . ." The commodification of care through cash and markets is consistent with the American character described by Clark, but there is another side to that character that also can be tapped. Given the activist histories of disability communities, the state and local control of disability policy, the profusion of voluntary agencies, and the widespread involvement of families in caregiving, a pro-community policy could nurture and structure that involvement and create a dialogue that leads to democratic and participatory choices, as opposed to market choices.

Policy Challenges

Like much of our social welfare programming, there are no easy choices about home care benefits. Fiscal pressures make it difficult to see sources for new federal funds without substantial realignment of current thinking about spending priorities and taxation burdens (Gist & Aleksa, 1994). Devolving responsibility to hard-pressed states and localities is more likely to result in a race to the bottom than in new funds. Yet, the numbers and needs of PWD's of all ages will rise sharply in the future, quite possibly overwhelming our already inadequate home care systems and further straining overburdened families.

My colleagues and I argued several years ago for a national home care entitlement (Leutz, et al., 1992), but a realistic benefit strategy must start where we are today, and that means states and Medicaid. Using Medicaid personal care and HCB waiver funds, supplemented by other smaller state and federal sources, there are sufficient resources in many states to pay for meaningful home care benefits for at least some groups of low income persons with disabilities. Some states also have pooled these resources to create administrative infrastructures that provide a single entry point to multiple sources of funds and that will pay for a wide range of HCB services up to benefit caps pegged at or below institutional spending.

Although some states approximate benefit adequacy in levels of resources, advocates for more choice and autonomy for PWD's have helped us to see that service users' wants and concerns are too often ignored even in the more comprehensive systems. But the call for more choice can be heeded in different ways, and how we respond will have profound consequences.

One path to choice and autonomy promises empowerment of PWD's as consumers in markets. Proponents of this path believe that public service and management systems cannot be reformed. It is better just to give people money, trust that the cash will stimulate a supply of preferred and affordable services, and let people find and buy what they want. I have argued herein that the free market will not offer adequate services without extensive regulation, that unfettered competition may drive out community-based providers, that many PWD's will need financial and logistical help as consumers, and that commodification is the wrong principle upon which to base home care benefits and services.


An alternative path is to try to empower PWD's by connecting them better with more active and organized communities at both state and local levels. This position holds that public management systems and professionals can change and grow stronger by work-

ing in partnership with service users and carers. It also posits that democratic community action is the path to deciding what services are needed, to developing self-help and community provider organizations, to monitoring the performance of administrative systems and providers, and to working through the relative needs and obligations of PWD's and family members based on life cycle factors.

The option of giving users cash rather than case-managed service benefits should be developed. It is an option which many PWD's and carers clearly want. But offering the cash option does not preclude the need for other administrative, provider, and professional reforms to increase respect for choice and autonomy.

The community development strategy for home care benefits will require modest new resources in three areas. First, assessment and care management systems need overhauling to ensure that users' and carers' views of problems and needs become the starting point in care planning. Training, as well as supportive administrative and advice structures are needed. Second, various initiatives and roles for users and carers will require operational support. These may include advice lines, self-help groups, new provider initiatives, community coalitions, advocacy organizations, and participation in policy-making and oversight groups. Third, definitions of services that are covered by benefits must be expanded to include family carers, privately hired aides, expenses for volunteers, community social agencies, social transportation, and other services deemed important by users and carers.

Beyond these actions specific to support of community-based home care benefits, broader actions would help significantly. These include finding the funds to support equitable eligibility by eliminating waiting lists and "no care zones," better coordinating health and long-term care benefits, and fixing deficiencies in income support programs that discourage PWD's from working and penalize family carers in pension and disability systems.

The poor public understanding of the limits on benefits for LTC is a barrier to improving these benefits, but it is also an opportunity. If we can construct service programs that have the active support and participation of PWD's, carers, and concerned professionals and other supporters, home care benefits and their gaps will become more broadly understood. Eventually, society may be more ready to put in the resources that will be needed so desperately for all groups in the future. 

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Independent Choices

Pamela Nadash

The consumer direction movement stems from the realization that, too often, people with disabilities and older persons are denied the opportunity to exercise choice and control over some of the most basic and intimate aspects of their day-to-day lives—the personal assistance and other long-term services they receive. It is argued that consumers who manage their own support services, either directly or through a chosen advocate, can develop a package of services that reflects their individual preferences and values to an extent unmatched by anyone arranging services on their behalf. Additionally, providing consumers with the option of managing and directing the long-term services they need is an acknowledgment that they are the best judges of their own needs and the best decision-makers on how these needs get met—an acknowledgment too often not made.

Consumer direction includes people with disabilities of all types and from all age groups. It also explicitly builds on work done by others. For example, many of the ideas that have been incorporated into consumer direction were actually developed first by independent living advocates and implemented by people in the mental retardation/developmental disabilities (MR/DD) world. The goal of consumer direction is to bring together the ideas developed in these many different worlds of disability and aging and the people working in these different areas of long-term services. In this way, the creativity and strength of these different groups can be combined to benefit all.

Having said that, it is recognized that services for older people are one of the most important targets for change. A disturbing proportion of those serving older persons with disabilities fails to acknowledge their right to make genuine decisions about their lives. Similarly, the structure of service delivery often fails to allow choice and control for older persons who use long-term services. Because older persons are the majority of long-term service recipients, these attitudinal and structural barriers affect the way that services are provided to all people who use long-term services. So if long-term services as a whole are going to be changed, the disability community (including older persons who are disabled) needs to acknowledge that, for most of the general public and for most legislators, long-term services are services for older people—and older people need to be protected. In practice, this often means that their freedom is restricted.

The financing of long-term services is another reason for the paternalism of the system. Administrators of public funds quite rightly feel a duty to ensure that funds are used in appropriate ways; voters and legislators alike demand this. Administrators, then, are all too aware of the possibility of misuse, and the scandal that would result. Consequently, programs are designed to allay those fears, often by placing limits on who can provide services. Such limits have further consequences: a lack of competition, consumers who have to “take what they can get,” and service providers that are not responsive to consumer needs. The pressure created by limits on budgets exacerbates the situation even further.

Despite the forces that make innovation in long-term services difficult, con-

sumer direction does seem to be the way of the future. There is evidence that program administrators are more aware of the movement and, to some extent, are making changes that integrate consumer choice into their service delivery systems. Certainly the initiatives described later in this article and elsewhere in this journal represent some important steps forward.

A similar wind of change is sweeping the rehabilitation world. According to a survey conducted by the National Council on the Aging¹, administrators of vocational rehabilitation (VR) programs are the least likely of those surveyed (who also included administrators of aging, Medical Assistance, and MR/DD programs) to report knowledge of consumer direction (85% of VR administrators versus an average 94% of other program administrators). VR administrators also expressed the least interest in advancing consumer-directed programs for persons with disability or older adults in their departments—63 percent of VR administrators expressed interest versus an average of 71 percent of other program administrators. They are also least likely to report that programs integrate some key features of consumer-directed programs, such as consumer control over choice and payment of providers.

However, it appears that changes will be coming soon. For example, it is notable that two bills addressing the same issue have been presented to the 105th

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Congress. Both the "Ticket to Work and Self-Sufficiency Act of 1998" and the "Work Incentive Improvement Act of 1998" bills seem to reflect a consensus that some change to the system is needed. Both of these bills would provide Social Security Disability Insurance (SSDI) recipients with a choice of service providers. While the prospects of these individual bills are uncertain, the spirit that inspired them is surely a sign of change.

What Is Consumer Direction?

Consumer direction is very much related to other notions, such as "self-determination," "independent living," and "autonomy." All of these ideas are linked by a similar insight—that individuals should have control over their circumstances—but have been developed within their own discrete worlds. To pull together these ideas, the National Council on the Aging (NCOA) developed the following definition of consumer direction in partnership with a variety of aging and disability groups:

"Consumer direction is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services received. Consumer direction may exist in differing degrees and may span many types of services. It ranges from the individual independently making all decisions and managing services directly to an individual using a representative to manage needed services. The unifying force in the range of consumer-directed and consumer choice models is that individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services."

This definition contains within it a number of important ideas. The most important of these have been identified as our key principles, which articulate some basic assumptions underlying the consumer-directed approach to systems

design and service delivery. Some of these key principles are that:

Systems should be based on the presumption that consumers are the experts on their service needs. This principle underscores the belief that an informed consumer is the best authority on what his or her service needs are, how these needs are best met, and whether these needs are being met appropriately. The consumer should be

Consumer direction is very much related to other notions, such as "self-determination," "independent living," and "autonomy."

presumed competent to direct services and make choices—regardless of age, nature, or extent of disability—just as ordinary citizens are presumed competent to make all manner of decisions about their day-to-day lives. Part of this presumption of competence is an understanding that even though information and other forms of support are necessary to enhance an individual's ability to make decisions they by no means compromise it.

The presumption of competence also means that a consumer's decision to delegate responsibility for directing certain aspects of service provision to other persons can be a consumer-directed choice, under the right circumstances, such as when a choice is based on sound information about service options and made in an environment in which viable choices exist. Several delegation arrangements can be considered consumer-directed:

- where a consumer freely chooses a representative to act on his or her behalf;
- where a consumer freely selects a service arrangement that manages services on behalf of the consumer; and

- where a person with cognitive impairment has a family member acting as a consumer on his or her behalf.

Another important element of this principle is the presumption that consumers are the best monitors of service quality, particularly when they have been provided with training that would help them to do this. Such training might involve basic information about consumers' medical conditions and the forms of assistance that would best maintain their functioning. It might also involve training on how to manage a worker so that services are delivered in the most appropriate way. This type of training could provide a more effective means of ensuring quality than any number of rules and regulations that attempt "top-down" quality assurance. What better way of ensuring the onsite oversight that is so lacking in the home care world? Rather than responding to a supervisor, who can have only a vague notion of a worker's capabilities, the worker would learn that he/she must respond to the consumer's authority.

Different types of services warrant different levels of professional involvement. The appropriate level of professional knowledge and expertise differs significantly among service types; for example, assistance with personal care activities and housekeeping does not require high levels of professionalism, while medical services do. The ability of consumers to assume full responsibility for services varies accordingly. Persons with disabilities, for example, are perfectly competent to determine their personal assistance and housekeeping needs, direct the delivery of services, and monitor the quality and appropriateness of services, particularly if they have access to information and other forms of support. As the complexity of the service grows, consumers become more reliant on the expertise of professionals to translate their needs into actions. However, the principle of consumer direction continues to apply even in complex situations; that is, consumers retain the right to participate in assessing need, evaluating options, deciding a course of action, and deter-

mining the appropriateness of that course of action.

Consumer direction poses a challenge to traditional assumptions held by many aging services and some disability services, which consider that professional intervention is not only appropriate but also required, based on the consumer's disability, age, or functional status.

Choice and control can be introduced into all service delivery environments. Systems can be designed to include a variety of options that cater to diverse groups of consumers, whether they wish to exert total control or very little control over services. Indeed, the range of preferences expressed by consumers opens up possibilities for enhancing consumer direction within many service delivery environments. For example, home health agencies can easily make changes to adapt to a consumer whose only strong desire is to control the choice of worker; other consumers' preferences will require a greater measure of change. Whatever the organizational restrictions posed by different service delivery environments, possibilities exist for enhancing consumer control.

Not only do consumer-directed service systems support the dignity of people requiring personal assistance, but they can be less costly when properly designed. There is evidence that, by cutting out much of the administrative overhead associated with home and community-based services that are either provided directly by government departments or contracted to private agencies, consumer-directed services can be less expensive than services delivered through traditional mechanisms. For example, some studies, here and abroad, suggest that efficiencies can be achieved through "cash and counseling" programs. However, there is much to be learned about the design elements that result in savings and about cost savings that can be achieved through other forms of consumer-directed service systems.

Consumer direction should be available to all, regardless of payer. Although the well-off have long been able to direct personal assistance services

according to their preferences, people who rely on publicly financed services or on services paid for out of insurance monies have much less control over the services they receive and have significantly less control than people who receive other forms of public assistance, such as Supplemental Security Income (SSI) or Aid to Families with Dependent Children (AFDC). Inability to control the form of assistance received is severely dehumanizing, particularly when payer control extends to issues concerning day-to-day existence (e.g., eating times or living environment). Disability, whether mental, physical, sensory, or age-related, when combined with reliance on public assistance should not provide a rationale for others to make decisions about every aspect of a person's life

These principles expand on many of the issues raised by the definition of consumer direction. However, they are not necessarily useful in determining whether a particular program or service is consumer-directed. One of the paradoxes facing those who hope to reform service delivery is that so many programs claim to be consumer directed but are not in practice.

Certainly, the official rhetoric that service providers are trained to embrace is very consumer directed. The difficulty, it appears, is that no amount of consumer directed rhetoric will ensure that consumers make decisions for themselves. To think that better training of case managers and other service providers is the answer ignores the structural basis of the problem—that consumers lack the power to have their decisions enforced. So long as consumers rely on the good intentions of another to ensure that their decisions are enforced, the ability to control their lives will elude them.

How does this rhetoric translate into reality? To make such a judgement, NCOA saw a need for criteria against which services could be assessed. To determine how consumer-directed a program is, the following elements need to be examined:

- *The ability of consumers to control and direct the delivery of services.* How

much control do consumers have over how, when, and by whom services are delivered, and to what extent do they determine the type and quality of services received? How easy is it for them to implement their service delivery preferences?

- *The variety and type of service delivery options actually available to consumers.* Do consumers genuinely have choices, ideally a range of viable service options, available? Are there any limits, risks, or restrictions to consumer control? Is the playing field level—for example, are all the options of roughly equal quality and cost to the consumer? Are consumers locked into a system once a choice is made?

- *The availability of appropriate information and support.* Are information and support available that enable consumers to take advantage of a consumer-directed system of service delivery? Are consumers informed about the options available and the personal, legal, and financial issues associated with these options? Are consumers provided with the support needed to make their choices viable, and can they be assured of continuing support once a decision is made?

- *The ability of consumers to participate in systems design and service allocation.* What level of participation do consumers have at the policymaking level—for example, in the overall design of service delivery systems? What means of redress is available to them? What is their level of participation in the service allocation process and who decides how consumers' needs are best met? Do consumers have the power to influence these or any other decisions?

Why Consumer Direction? Why Now?

Although much of the inspiration behind consumer direction began with the independent living movement—which started in the late 1960's, when people with disabilities began to demand the right to participate fully in society—the reasons it has taken off have been more varied. Part of the reason lies in an awareness that future

recipients of publicly funded long-term services are likely to be very different from many of current recipients of those services. Services will need to change in response to these different expectations. In particular, they will need to respond to yet another demanding population: the people with disabilities who are now living into old age.

People growing into old age now have had a lifelong experience of being demanding and discerning users of services and purchasers of products. They are accustomed to living in a consumer-oriented society. In contrast, many of those who are currently in the older age groups were marked by other experiences, such as living through the Great Depression, when people took what they got and were grateful for it. Such generational experiences are reflected in people's attitudes toward the long-term services they receive.

In addition, the majority of those currently using long-term services are older women who, generally speaking, have not had a lot of experience in controlling their lives. In contrast, women who are currently aging into the use of long-term services have had more experience of control over their lives. Consequently, their demands and expectations of aging are likely to differ from the current cohort of aging persons.

Yet another factor in the changing service environment is the increased need to respond to payer's needs. More and more, public payers are encouraging the use of market forces to help determine which services are most suitable for consumers. More and more, providers will need to compete for business from consumers, managed care organizations, and public payers. These changes will force service providers to become more responsive to consumer needs.

Increased competition is at least in part due to a belief that competition yields improvements in the quality of long-term services. Consumer direction increases competition, but it can also be seen as another type of response to the need for improved quality assurance mechanisms. Program administrators are acutely aware of the short-

comings of top-down structural and procedural methods of assuring quality: the record of success has not been as strong as it could be; they are expensive to administer and monitor properly; and they can limit flexibility in service delivery. Rather, consumers can be used to provide ongoing feedback on the performance of the service provider. To often, however, this feedback is limited to crude measures of overall satisfaction; rather, administrators could be using consumers' onsite monitoring capabilities to assess objective features of service delivery, such as timeliness, appropriateness of service, and other service delivery features.

Additionally, quality can be improved by giving consumers a greater ability to enforce their requirements of service providers—by giving consumers who would like this responsibility the power to hire and fire, for example. This form of quality assurance is particularly suited to long-term services because, unlike other products on the healthcare market (such as health insurance or specialist services), the quality of the services is fairly transparent to users. Also, because of the long-term nature of their condition, consumers are often knowledgeable about their long-term service needs. With appropriate training, consumers who want to take on this role can be highly effective in ensuring that services are delivered the way they want. And who besides the consumer has more of an interest in ensuring that services are high quality?

Still another factor that consumer direction responds to is the increasing scarcity of suitable personal assistants. Many consumer-directed programs make it possible for consumers to choose from a wide variety of service providers, sometimes even from family members. By choosing a worker who has some personal connection with the consumer—whether that be because they are neighbors, fellow churchgoers, or relatives—services may be more reliable and responsive. Consumers in rural areas may be able to find local providers when they are not restricted to agency rosters.

Efforts to Develop Consumer Direction

The trend toward consumer direction has very much been embraced by those who hope to improve service delivery. Major players include charitable foundations such as The Robert Wood Johnson Foundation (RWJF), which is funding a number of initiatives in this area; federal policymakers, especially the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the U.S. Department of Health and Human Services; state-level policymakers; and advocacy groups such as The National Council on the Aging.

Three major RWJF projects are the *Cash and Counseling Demonstration and Evaluation Project* (discussed in two other articles of these special issues of *American Rehabilitation*, the evaluation is funded by ASPE); the *Self-Determination for People with Developmental Disabilities Project*; and the *Independent Choices: Enhancing Consumer Direction for People with Disabilities* grants program. All of these three projects represent important steps in making consumer direction a reality.

Self-Determination

The *Self-Determination Project* grew out of a local project developed by Monadnock Developmental Services, Inc., (MDS) in New Hampshire, which aimed to show that consumer direction was appropriate for people with cognitive impairment. It was awarded a 3-year demonstration grant from RWJF—starting in 1993—to address three major problems in New Hampshire's developmental services program: the high costs of care, the increasing waiting lists, and consumer dissatisfaction with the ways in which support was provided. MDS has put into practice the guiding principle of self-determination, "the idea that people with disabilities will determine their own future, with appropriate assistance from families and friends"; MDS has also tried to put into practice the belief that individuals with disabilities should have both the means (funding)

and the authority (through the planning process) to plan their own lives.

Out of this project was developed another, more ambitious project, also funded by RWJF. *Self-Determination for Persons with Developmental Disabilities* is a \$7 million grants program; its National Program Office is based at The University of New Hampshire Institute of Disability. The aim of the program is to jump-start states' long-term support systems for persons with developmental disabilities, enabling them to become contributing members of their communities. Nineteen states are receiving grants to initiate system changes and translate these changes into meaningful reforms for significant numbers of persons with disabilities in at least two communities in each state. (Awards were made in January of 1997.) Ten more states are receiving smaller grants to provide technical assistance to local communities that are attempting to make systems changes.

Some exciting developments have already taken place. Hawaii, for exam-

ple, has passed legislation authorizing individual budgets for people with developmental disability. With individual budgets, people are given a set amount of money that can be used to access a wide range of supports, including personal assistance and other services that support community living. Minnesota has accomplished a similar end by obtaining approval from the Health Care Financing Administration (HCFA) to add self-directed supports to the list of

Medicaid services it supplies under its MR/DD home and community-based waiver. And Michigan has a waiver application pending that would meld managed care with self-determination.

Independent Choices

Independent Choices: Enhancing Consumer Direction for People with Disabilities is a \$3 million national grants program of RWJF. Its aim is to foster the development of consumer-directed home and community-based services for people by funding 13 demonstration and research projects. Importantly, grants are not restricted to an age group or to a particular set of disabilities, allowing parallels to be drawn between different populations and service delivery systems.

Four research projects are helping to expand knowledge about consumer direction. One of the most common questions is whether consumers actually want consumer direction and how preferences for it might differ among groups of consumers. Looking specifically at the question of how different groups of ethnic elders vary in their desire for consumer direction is the *Elder Preferences For Consumer Direction* project, conducted by Mark Sciegaj of the Institute for Health Policy at The Heller School of Brandeis University. Another project, conducted by Larry Polivka and Jennifer Salmon of the Florida Policy Exchange Center on Aging, University of South Florida, looks at *Factors That Influence Consumer Choice*.

The aim of this project is to determine the extent to which choice and control are instrumental in a consumer's decision to receive long-term services and the quality of life when receiving services; the project will compare older people living at home and in assisted living.

Yet another research project deals with family members who act as decision-makers for people with cognitive impairment. *Making Hard Choices: Respecting Both Voices* is a project of Lynn Friss-Feinberg at the Family Caregiver Alliance in San Francisco and explores

the decision-making process and perception of choice in service options for adults with mild to moderate cognitive impairment and their family caregivers. Lastly, the *Evaluation of a Consumer-Driven Personal Care System* is being conducted by Kris Hagglund and Mary Nack of the Rusk Rehabilitation Center at the University of Missouri-Columbia. This project will evaluate a consumer-directed personal care program that is integrated into a Medicaid managed care delivery system for people with physical disabilities.

The nine demonstration projects cover a wide range of issues. Three will test structural innovations in the delivery of long-term services. *Consumer Direction In Ohio's PASSPORT Program*, conducted by Suzanne Kunkel, Pam Mayberry, and Marisa Scala of the Scripps Gerontology Center at Miami University, will allow consumers in Ohio's existing home and community-based Medicaid waiver program to use a menu of service options—fiscal intermediary services, flexible care planning, and self-directed case management—and develop training programs on consumer-directed options. *Consumer-Directed Independent Choices*, run by Julia Huddleston of Oregon's Senior and Disabled Services Division, will allow Medicaid consumers to use cash to purchase long-term services, in an effort similar to the *Cash and Counseling Demonstration and Evaluation*. The third, *Consumer-Directed Personal Assistance Program for the Cognitively Impaired* applies a consumer-directed model to a unique population. Conducted by Jean Marks of the New York City Chapter of the Alzheimer's Association, this project will implement and evaluate supportive services, such as training and education on personal assistance services, that will enable persons with Alzheimer's disease and their families to participate successfully in a consumer-directed program.

Yet another project will look specifically at the supports needed for persons participating in a consumer-directed program. The *Consumer Support Training Demonstration*, conducted by Nancy Eustis at the Hubert H. Humphrey

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ple, has passed legislation authorizing individual budgets for people with developmental disability. With individual budgets, people are given a set amount of money that can be used to access a wide range of supports, including personal assistance and other services that support community living. Minnesota has accomplished a similar end by obtaining approval from the Health Care Financing Administration (HCFA) to add self-directed supports to the list of

Institute of Public Affairs at the University of Minnesota, is a partnership with the Minnesota Department of Human Services to support the state's Consumer Support Grant Program, which allows consumers to receive cash for long-term services. It will develop supports for CSG participants, provide them with cash management skill, and evaluate the support provided.

Another project aims to make home health agencies more consumer directed. *Incorporating Independent Living Philosophy into Home Health Agencies* is run by Diane Coleman of the Progress Center for Independent Living in Forest Park, Illinois. The Progress Center

Consumer direction means not only respecting other cultures' preferences regarding long-term services, but also conducting projects in a consumer-directed way.

and Lutheran Social Services, a home health agency, are working together to make services more consumer responsive; the project will also develop a manual for other centers and home health agencies across the country.

The *Rapid Response Worker Replacement* project aims to tackle a problem experienced by users of personal assistance everywhere: their need for personal assistance at short notice. It seeks to demonstrate a cost-effective and consumer-driven system of emergency PAS, to increase consumers' safety and security, reduce use of 911 and emergency room services, and develop a model of emergency backup services that can be replicated nationally. Deborah Doctor of the Public Authority for In-Home Supportive Services in

Alameda County, California, is conducting this project.

Consumer direction means not only respecting other cultures' preferences regarding long-term services, but also conducting projects in a consumer-directed way. The *American Indian Choices: Culture and Context* project will develop, demonstrate, and evaluate the application of a "talking circles" model to creating long-term service options that are consistent with tribal resources, cultural considerations, and the spirit of consumer choice. LaDonna Fowler at the University of Montana Rural Institute on Disabilities conducts the project.

Another project tries to use consumer cooperatives to increase the benefits and efficient use of personal assistance services (PAS). The *California PAS Consumer Co-op Project* is headed by Barbara Wheeler of the Children's Hospital University Affiliated Program at the University of Southern California in Los Angeles. Four project partners will develop, implement, and evaluate the co-ops.

Lastly, *Promoting State Policy Reform to Enhance Consumer Direction* aims to work with state agencies to achieve changes in policy by infusing consumer-directed principles and practices into the design, management, and delivery of community-based services programs. Virginia Dize at The National Association of State Units on Aging in Washington, DC, will prepare a guide that will provide a protocol for identifying prevailing policies and practices that impede consumer direction; the project will work with identified states to implement changes.


Consumer-Directed Durable Medical Equipment

In yet another initiative to use the power of consumers to improve service quality, HCFA is inviting centers for independent living (CIL's), to test a model of consumer-directed durable medical equipment (CD-DME) for Medicare beneficiaries. Demonstration participants will provide assistive technology information and facilitate consumers' access to expert assessment

and care coordination. In partnership with consumers with physical disabilities, participants will work to acquire Medicare-financed DME products and services more efficiently, using a prior authorization claims process. Savings accrued by this more efficient purchasing will then be (1) used to establish beneficiary credit accounts that may be used by beneficiaries to obtain enhanced equipment and/or services not covered by Medicare, and/or (2) considered as potential Medicare program savings.

Once payment is authorized, a credit account will be maintained with funds that the consumer may draw upon to acquire equipment, with any unspent balance available for additional features, equipment maintenance, or for other wheelchair DME-related needs not subject to Medicare coverage rules. Four grants will be awarded in late summer 1998.

Conclusion

Consumer direction responds to a number of important needs that currently exist in the long-term services arena: the changing cohort of aging persons; the changes in attitude toward disability exemplified by ADA; the need for incentives to providers that result in consumer-oriented behavior; the shifts in approaches to quality improvement; and the need for innovation in long-term services. Until recently, only a few isolated programs put consumer direction into practice. Evidence was lacking that would address the concerns raised by the skeptics. With recent initiatives, however, a body of knowledge should arise that will set consumer-directed practice on a firm basis for the future. 

Note

1. National Institute on Consumer-Directed Long-Term Services, *State Administrator Knowledge, Practices, and Attitudes Regarding Consumer Direction*. Washington, DC: National Council on the Aging. March 1998.

You Can Do It:

State Initiatives Broaden Access to Consumer-Directed Personal Assistance Services Through the Use of Intermediary Service Organizations

Part One of Two

*Susan A. Flanagan, MPH
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States have been providing personal assistance services (PAS) to persons with disabilities and chronic conditions for well over two decades through Medicaid and state-funded programs. These services have traditionally included assistance with the basic activities of daily living (ADL's), such as bathing, dressing, grooming, and transferring, as well as assistance with instrumental activities of daily living (IADL's), such as shopping, housecleaning, and meal preparation, and may be delivered in the home, the workplace, and in a recreational setting. Recently, a growing body of literature has brought to a wide audience good news about a mode of service delivery that embodies many of the principles of today's consumer-oriented healthcare goals: consumer-directed personal assistance services (CD-PAS) (Scala & Mayberry, 1997; Richmond et al., 1997; Doty et al., 1996; Sabatino & Litvak, 1995; Flanagan, 1994; DeJong et al., 1992; Sabatino & Litvak, 1992).

Consumer-directed modes of financing and delivering personal assistance services permit a person with a disability comparatively greater choice and control over all aspects of service provision, including:

- choice of provider,
- selection of services and related supports,
- service plan and schedule, and
- ongoing management of services (Sabatino & Litvak, 1992).

CD-PAS differs from traditional agency-based PAS in that the individual served (the consumer) exercises choice

and control over the nature, scope, and level of services he or she receives from the provider, instead of the provider having most, if not all, control over how, when, and where service is delivered (Doty et al., 1996).

No single service delivery model encompasses the entire range of possible varieties of CD-PAS that might exist but, in general, a service can be described as consumer-directed if the persons receiving the service are responsible for selecting their attendant(s), setting the terms and conditions of work, taking on the administrative responsibilities of an employer (payroll, taxes), supervising, disciplining, and, if necessary, terminating the employment (Doty et al., 1996). Moreover, some CD-PAS programs allow a consumer to have a representative (e.g., family or nonfamily member) manage the employer-related responsibilities associated with an attendant on the consumer's behalf (as in the case of a person who may have a cognitive impairment or mental retardation). Permitting representative participation can greatly increase consumers' access to CD-PAS.

When a third party payer finances PAS (e.g., private insurance or publicly-funded programs such as Medicaid), certain limitations may be placed on the consumer's ability to exercise choice and control over his or her PAS. These include prohibitions on providing cash benefits, hiring family members, and on the range of allowable services the attendant may perform. Public payers may also require training and certification of attendants, nurse supervision, and conduct of criminal background checks.

There are advantages to all stakeholders in allowing consumers more choice, autonomy and control over their

PAS. Consumer advocates of CD-PAS programs argue that persons with disabilities and chronic conditions are self-directing consumers of services and should be afforded as much independence and autonomy as possible in decisions regarding the types, amounts, and sources of PAS they can access (DeJong et al., 1992; Doty et al., 1993). Being allowed to direct their own PAS means consumers get the services most desired and needed and on the terms most convenient for them. For example, this might mean being able to access PAS before 8 a.m. or after 5 p.m. to accommodate a consumer's work or school schedule, having services provided at work or school in addition to receiving them at home, and purchasing services at an hourly rate significantly lower than traditional agency-based PAS.

For the state, allowing the consumer to assume greater responsibility relieves the state of some of the day-to-day responsibilities of managing the services while providing PAS that more appropriately reflect the diverse needs and

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desires of the service populations. Program administrators also may see CD-PAS programs as a way to reduce the administrative overhead costs associated with the provision of traditional agency-based PAS and to achieve overall budget savings and efficiencies by downsizing government through the privatization of government functions.

However, with increased consumer choice, autonomy and control come responsibilities arising from a myriad of state and federal statutes and regulations. States implementing CD-PAS programs must find a way to strike a satisfactory balance among a number of competing factors:

- the consumers' desire for CD-PAS and their varying abilities and desires for choice, autonomy, and control,
- states' duty to ensure that applicable federal and state tax and labor laws and regulations are followed and CD-PAS programs and funding are properly administered,
- states' desire not to be the employer of record of CD-PAS attendants, and
- states' duty to assure that the health and safety of all beneficiaries are safeguarded (Flanagan & Green, 1996; Doty et al., 1996; Sabatino & Litvak, 1995).

Using intermediary service organizations (ISO's), has proven to be an innovative way of helping states achieve the best balance among competing policy objectives (Flanagan & Green, 1996; Sabatino & Litvak, 1995; Flanagan, 1994).

How Intermediary Service Organizations Help the Stakeholders Achieve the Best Balance Between Competing Goals

As states have experimented with consumer-directed personal assistance services over recent years, they have discovered that such services can successfully be made available to consumers of varying desires and abilities for self-direction, provided that supports are available and tailored to the specific needs of consumers. A number of states have found that they can contract with a new provider type, the ISO,

to provide the range of fiscal, administrative, and support services to enable consumers of varying desires and abilities to effectively manage their CD-PAS. In the same way that consumers now buy tax, accounting, and payroll services from such organizations as H&R Block and Paychex, Inc., consumers with disabilities and chronic conditions in many state and Medicaid-funded CD-PAS programs can now obtain the intermediary services they need to manage their own personal assistance services.

An ISO may act directly as the fiscal agent for a consumer. As the fiscal agent, its job is to calculate, withhold, and file Social Security (Federal Insurance Contribution Act, or FICA) and Medicare taxes, federal and state unemployment taxes (Federal Unemployment Insurance Act, or FUTA, and State Unemployment Insurance Act, or SUTA), and other statutory benefits (e.g., state disability insurance and workers compensation insurance) and produce and distribute attendant payroll checks. The ISO may also broker and administer attendant fringe benefits if available. On the other hand, the ISO may simply assist consumers by providing them with skills training on how to hire attendants, manage their employment taxes and payroll, and supervise attendant activities. An ISO may also provide additional supportive services, such as maintaining an attendant registry, conducting criminal background checks, assisting consumers with developing emergency backup service plans, performing consumer assessments, and providing self-advocacy, peer counseling, and case management. The main point to keep in mind is that there is no single set of services that an ISO must provide. Rather, intermediary services should be developed to reflect the needs and desires of the service population and selected by a consumer and his or her representative, when appropriate, on an as needed basis.

Recent research has identified six discrete models of ISO used by states in the study (Sabatino & Litvak, 1995;

Flanagan, 1994). These are briefly described in the following:

Fiscal Conduit ISO. As the name implies, the role of this ISO largely consists of disbursing funds to consumers directly. The consumer is the employer of record and performs all administrative and supervisory work connected with employment of his or her attendant. This is the most cost efficient method of administering a CD-PAS program and provides consumers with the highest level of consumer direction. The model also requires only a minimal level of state program oversight.

IRS Employer-Agent. This is a government entity approved by the Internal Revenue Service under Revenue Procedure 80-4 to act as a fiscal agent for consumers for the purpose of preparing and filing employer-related taxes (e.g., FICA, FUTA/SUTA). The consumer is the employer of record of the attendant. This ISO may also prepare and distribute payroll checks and process attendants' time sheets. This model provides consumers with a high level of consumer direction and reduces their administrative burden while achieving regulatory compliance.

Vendor Fiscal ISO. This ISO performs the same tasks as the IRS employer agent but is a private vendor under contract to the state. Not only does this model provide a high level of consumer direction and reduce the administrative burden for consumers, it also assures both the consumer and the state that regulatory compliance related to employment taxes is achieved. It also reinforces the fact that the consumer, rather than the state, is the employer of record.

Supportive ISO. This ISO model may provide supportive services to consumers, such as skills and self-advocacy training, assistance with criminal background checks, development of emergency backup service plans, and maintenance of an attendant registry that assists consumers in performing the employment-related administrative and supervisory tasks associated with their CD-PAS. Supportive services may be provided by a distinct vendor or through another ISO model offering a

No single service delivery model encompasses the entire range of possible varieties of CD-PAS that might exist. . . .

range of services (e.g., *Agency with Choice* or *Spectrum ISO*).

Agency with Choice. Under this ISO model, the agency is the employer of record of the PAS attendants and, therefore, is responsible for the administrative tasks associated with employment. However, consumers are considered the *managing employers*, responsible for selecting their attendants and managing the day-to-day activities of their attendants to the extent that they wish to do so. The ISO may also perform background checks, maintain an attendant registry, and provide skills and self-advocacy training for consumers and direct care skill training, as needed, for attendants.

Spectrum ISO. This operational model provides a full range of administrative and management services to consumers under one umbrella organization. It allows consumers to select the services that best suit their needs at any given time. Under this model, the consumer may or may not be the employer of record, but the consumer is considered the managing employer and is often responsible for selecting attendants and managing his/her day-to-day activities to the extent that the consumer wishes (see Figure I).

What ISO model(s) and intermediary services work best under what circumstances? What ISO model(s) enable states to serve the largest number of eligible consumers? What are the challenges and opportunities afforded by this new service modality? These are some of the questions an ASPE-sponsored study of 23 CD-PAS programs in 11 states sought to answer. The balance of this article describes the ASPE-sponsored study conducted by The MEDSTAT Group, presents key

study findings, and discusses the major points key stakeholders should keep in mind when implementing consumer-directed programs using ISO's.

The MEDSTAT Group Study

In 1995, the Division of Aging Long-Term Care Policy (DALTCP), Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services, commissioned a study of the ways states were using ISO's to enhance the delivery of CD-PAS. The goals of the study were: (1) to find out how states were using ISO's to help consumers with disabilities and chronic conditions of all ages using CD-PAS fulfill their responsibilities as employers and (2) to provide the most concrete and practical advice possible to state program administrators and other interested parties through the creation of an informal information manual on CD-PAS and the use of ISO's.¹

Previous studies had shown that states were beginning to use ISO's to:

- increase access to CD-PAS to consumers with varying desire and ability,
- assist them in managing the employer-related responsibilities related to CD-PAS, and
- reduce the administrative burden related to CD-PAS.

This study built on earlier research by focusing special attention on the practical and legal challenges arising from the use of ISO's.

Twenty-three different CD-PAS programs in 11 states were studied and six ISO models were identified, as described earlier.² Data was collected through interviews with key program administrators, ISO providers, elder and disability advocates, consumers, and attendants in each study state. Each CD-PAS program and ISO studied was profiled and key employment tax, labor law, and licensing (in particular, state nurse practice acts) issues arising from the use of these ISO's were identified. Analysis of issues which cut across all CD-PAS programs and ISO models resulted in the development of "best practice" recommendations for resolving

these issues. In addition, the study team collected and reviewed written contracts used by the key stakeholders in the CD-PAS programs to determine their current use and best practices.

Findings from the Study

Matching Intermediary Services with Consumers' Desires and Abilities: The Need for Flexibility. The study team found that in choosing an appropriate ISO model for a CD-PAS program, state administrators need to focus on two principal characteristics: these are *the desire* and *the ability* of the consumer to perform the wide range of employer-related tasks associated with CD-PAS (see Figure II). In looking at the populations served by the different state programs, considerable variation was found in the consumers' desires and abilities to manage the employer-related tasks. The types and amounts of assistance offered by the different CD-PAS programs varied accordingly. For example, being the employer of record was important to many working age adult CD-PAS users, but it was viewed as less important by elders, persons with developmental disabilities, and their representatives. To such individuals, being the managing employer of their attendants and overseeing their daily activities was often more important than performing the payroll and tax functions.

The majority of consumers interviewed reported that it was very empowering for them to distribute their attendants' payroll checks after they had been prepared by the ISO. This reinforced the consumers' role as the manager of their attendant(s). However, many of the Medicaid-funded CD-PAS programs studied required the *IRS Employer Agent* or *Vendor Fiscal ISO* to distribute attendants' payroll checks directly to them.

The most successful CD-PAS programs were the ones that provided consumers of differing desires and abilities with a high level of consumer choice and direction and program flexibility related to the type and timing of delivery of PAS and the ability to select and manage their attendants.

Figure 1

ISO Models Operationalized as a Spectrum ISO

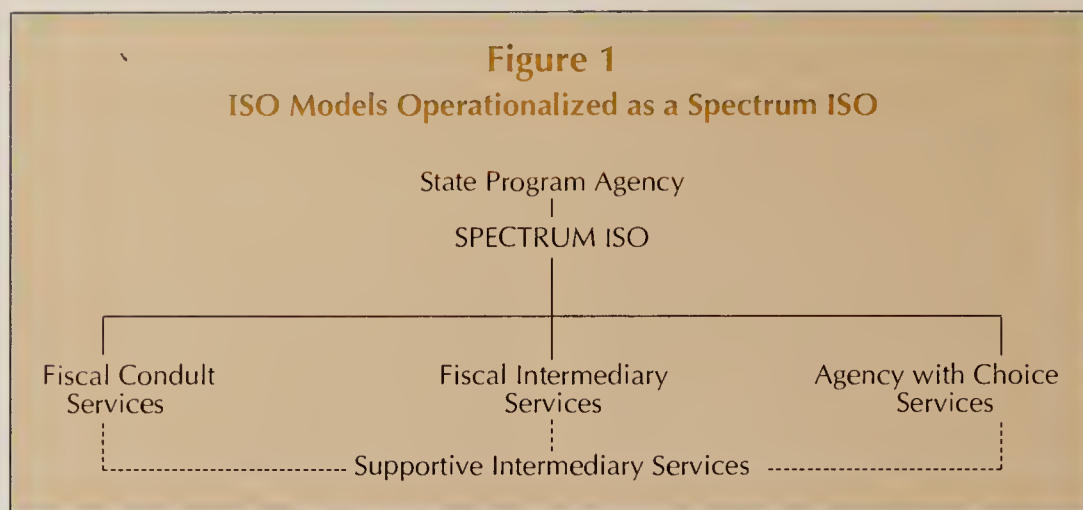
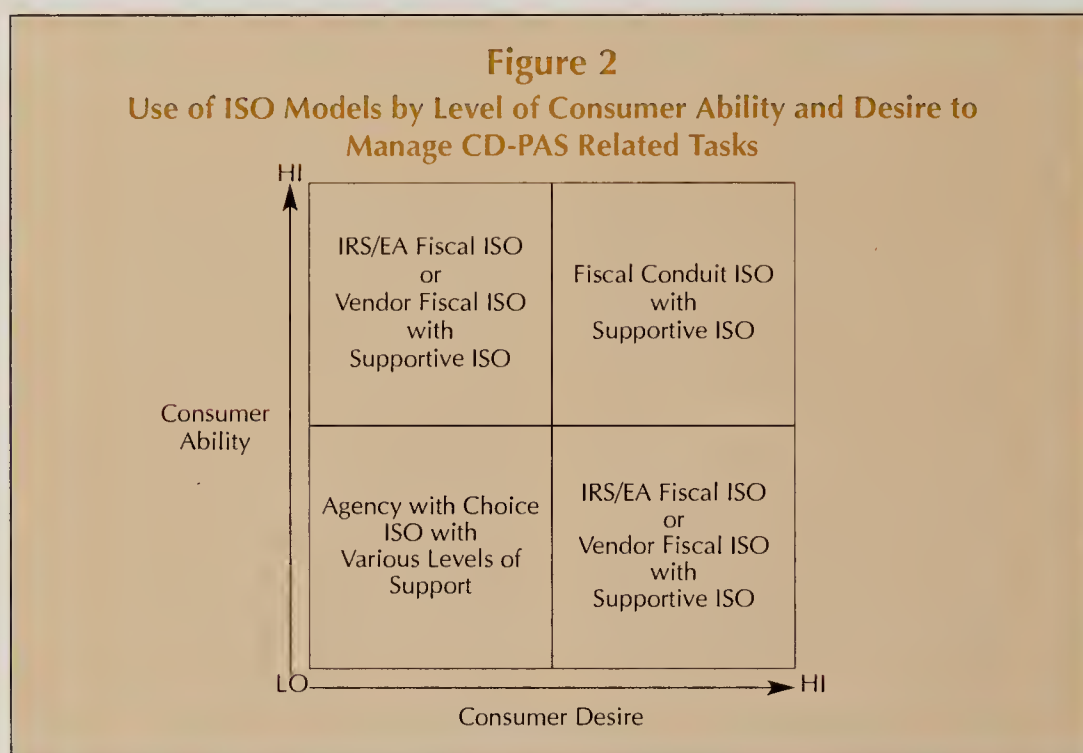


Figure 2

Use of ISO Models by Level of Consumer Ability and Desire to Manage CD-PAS Related Tasks



Meeting Legal Requirements: Identifying the Employer and Allocating the Employment-Related Tasks. The study team found that ISO's assisted states in meeting all of the legal and administrative requirements arising from the employment relationship. The *Fiscal Conduit ISO*, for example, worked best for consumers with high levels of both desire and ability to perform the employer-related tasks associated with CD-PAS, since only the most simple administrative services are offered (e.g., disbursement of funds, time sheet collection). Under this ISO model, the consumer achieves a maximum level of choice, autonomy, control, and program flexibility while being wholly responsible for the majority of administrative

and management functions (including employment taxes) an employer must comply with. When the consumer is able and willing to discharge these responsibilities, all works well and the state may achieve some program efficiencies. However, even in such a population, employment tax compliance may not be perfect. If compliance with managing employment taxes is not uniformly achieved, the consumer and the state can be at risk of liability for the failure to pay employment taxes. This is so even though the state may assert that the consumer is the employer of record of his or her attendant(s) and he or she (not the state) is, therefore, legally responsible for complying with the tax laws. As a result, the *Fiscal Conduit ISO*

model is best suited to a highly motivated and able consumer population.

To minimize the risk of noncompliance with employment tax and other federal and state regulatory requirements, some states directly assume the role of fiscal agent, managing the employment taxes (and state-specific disability and worker's compensation insurance, when appropriate) and payroll on behalf of the consumer. Consumers are the employer of record of their attendants and manage their day-to-day activities. Some states in the study chose to take on these legal and administrative tasks directly (e.g., the *IRS Fiscal Agent ISO* model); while others contracted with a vendor to perform these tasks (e.g., the *Vendor Fiscal ISO* model).

In the case of the *IRS Fiscal Agent ISO* and the *Vendor Fiscal ISO* models, the consumer is the employer of record and engages the ISO as his or her agent to ensure compliance with all applicable tax laws and regulations. However, it was found that even when a state contracted with an agency to be the legal employer of record of the attendant instead of the consumer, as in the case of the *Agency with Choice ISO* model, consumer choice, autonomy, control, and overall satisfaction could be maintained if the agency asserted a philosophy that reflected the basic goals of the independent living movement.

In sum, states that used ISO's to assist consumers with managing their CD-PAS were able to enhance and preserve consumers' choice, autonomy, and control related to their PAS while achieving the necessary compliance with critical tax and regulatory requirements in a timely and professional manner. The keys to success in implementing CD-PAS programs and ISO's that successfully meet the needs, desires, and abilities of consumers and result in full tax compliance lie in careful design and advance planning, educating all stakeholders regarding their roles and responsibilities, and drafting clear agreements reflecting the expectations and responsibilities of all parties to the employment relationship.

Even the Most Independent Consumer May Wish to Receive Some Support from Time to Time. Even though many consumers were willing and able to perform all employment-related tasks, the study team found that the most successful CD-PAS programs provided intermediary services at the request of consumers to enhance their management of their PAS. For example, a number of consumers expressed a desire to receive assistance in recruiting and screening prospective employees (including performing criminal record background checks). Consumers also expressed interest in receiving skills training in such areas as budgeting, employment tax and payroll preparation, and general management (in particular, training in employee discipline and discharge techniques). Perhaps the most frequently mentioned service need was for assistance with developing backup plans and obtaining relief attendants. Even the most independent person reported having difficulty at one time or another engaging attendants with short notice (e.g., when an attendant fails to report for work), at night, and on weekends and holidays. Having access to a critical number of key support services when consumers needed them most made good programs even better and greatly increased the consumers' ability to effectively manage their PAS and live successfully in the community.

Using ISO's: What You Need to Know

Important Conditions for States in Designing and Implementing CD-PAS Programs Using ISO's. States considering using ISO's to enhance the delivery of CD-PAS services to consumers with disabilities and chronic conditions of all ages must initially identify the needs of the service populations carefully in order to match the services and supports offered with the needs, abilities, and desires of consumers. After that, successful CD-PAS and ISO design and implementation depends on:

- choosing ISO's that are knowledgeable and able to comply with the

myriad of federal and state tax, labor, health, and safety requirements affecting consumers and attendants; and

- choosing ISO's that are sensitive to disability issues and embrace the independent living movement's philosophy of autonomy and consumer direction.

Legal Considerations

The laws and regulations affecting personal care attendants are complex and evolving, but the trend that most commentators discern favors viewing PAS attendants as household employees, not independent contractors.³ As such, personal care attendants are *someone's* employees and their employer is responsible for preparing, withholding, and filing employment taxes required for such household employees.

Some states have simply assumed that PAS attendants are independent contractors and are therefore on their own when tax time comes. Others have come to the conclusion that attendants are indeed employees, but they expect the consumer to do all the employer-related work, because the consumer is the employer of record. While it is appropriate and even desirable for the state to designate the consumer as the employer of record, the study team found that it is unrealistic to assume that in all cases the consumer is able or willing to assume responsibility for all employer tasks. A CD-PAS program that uses an ISO (in particular, a *Spectrum ISO*) recognizes the varying levels of consumer skills and desires and offers a range of services and supports.

States considering implementing CD-PAS programs with ISO's, and even states with CD-PAS programs already using ISO's, must, at a minimum, be familiar with federal tax and labor law requirements (and their state cognates) affecting domestic employees. This means learning about FICA, FUTA, SUTA, OSHA, and the minimum wage and overtime laws contained in the federal Fair Labor Standards Act (FLSA). There may also be tax, licensing, and labor laws in individual states that have an impact on domestic employees. Whether a fiscal agent assumes the re-

sponsibility for fulfilling these requirements on behalf of a consumer (as in the case of the *IRS Employer Agent* or *Vendor Fiscal ISO*) or expects the consumers to fulfill them, the point to remember is that compliance is *someone's* responsibility. Early recognition of the service population's needs and issues and good CD-PAS program and ISO design and development are essential.

Philosophy of the ISO

No matter whether the ISO is a full-service entity (e.g., an *Agency with Choice* or a *Spectrum ISO*), or simply provides tax and payroll services (e.g., an *IRS Employer Agent* or *Vendor Fiscal ISO*), the key to success for an ISO is its philosophy towards serving persons with disabilities and chronic conditions of all ages, in particular its commitment to the independent living philosophy. A fundamental premise of this philosophy is that persons with disabilities are self-directed consumers of services capable of managing their lives and that persons with disabilities and chronic conditions are "handicapped" primarily by barriers in their environments (in particular the absence of PAS), rather than by their disabilities (DeJong, et al., 1992). Even when many administrative and payroll tasks are performed by the ISO, such as in the case of the *Agency with Choice ISO*, the key is the level of involvement consumers have in the selection and management of their attendants. Agencies whose activities and orientation most closely conform to the goals of the independent living philosophy were most likely to achieve high levels of consumer satisfaction no matter which ISO model is used. Thus, contracts between states and ISO's should include performance standards that can be used to evaluate not only an ISO's administrative activities but also its commitment to consumer-directed principles.

Important Considerations for Consumers and Advocates. Consumers and advocates should realize that there are many ways to integrate ISO services into consumer-directed programs, just as there is much diversity in consumers'


needs, desires, and abilities. Because one size does not fit all, consumers are best served by CD-PAS programs that maximize not only autonomy and control, but choice and flexibility. A good consumer-directed program uses an ISO that provides a wide choice of service and support options.

One of the most important findings from the study is that the needs and abilities of consumers vary not only over their lifetimes, but also over much shorter spans. For example, some consumers may choose to hire an independent PAS attendant during the week when it is imperative to receive their PAS early so that they can arrive to work, school, or other appointments in the community on time. However, on weekends, it may be more difficult to recruit and retain independent attendants and the consumer may have more flexibility over his or her schedule. Under these circumstances, the consumer may choose to purchase his or her PAS from an agency (or optimally an *Agency with Choice ISO*). By the same token, some consumers are eager to take on all of the employer-related tasks when they enter a CD-PAS program. However, later they find that their need/desire for support services has increased (e.g., life just gets busy). It is in these situations that consumers may wish to receive additional support services to assist them in managing their CD-PAS.

Can consumers receive support services and still remain independent and manage their CD-PAS to their satisfaction? To cite only one example from the study, an *Agency with Choice ISO* was the employer of record of the personal care attendants for over 400 consumers with disabilities. The ISO was the employer of record for consumers' attendants and managed all the paperwork related to hiring and employer-related tax and payroll tasks, including the brokering of benefits and legal tasks related to the attendants. Yet, when asked who was the employer of their attendants, consumers unanimously responded that they themselves were

the employers of their attendants. This incorrect but positive response was due largely to the fact that these consumers managed those aspects of the employer-employee relationship that most mattered to them: choosing the services they needed and how and when they are delivered; selecting, training, and discharging their attendants; and reviewing and signing attendant time sheets and distributing attendant paychecks on a weekly basis.

To ensure that all persons with disabilities and chronic conditions who need PAS and wish to direct their services have access to CD-PAS programs, consumers and advocates should get involved in all aspects of the design and implementation of CD-PAS programs and ISO's. A key issue to be stressed with state program administrators is the ongoing need for the full range of intermediary services and the flexibility to choose only the services that are most needed.

This study indicates that the ongoing emphasis of the basic tenets of the independent living philosophy, together with the current trend in public health policy towards consumer empowerment and responsibility, makes this an auspicious time to use this new service modality. Thoughtfully implemented, ISO's expand the availability of consumer-directed personal assistance programs to persons with disabilities and chronic conditions of all ages. 

Notes

1. Flanagan, S.A., & Green, P.S. (1996). *Consumer-Directed Personal Assistance Services: Key Operational Issues for States CD-PAS Programs Using Intermediary Service Organizations*. Copies of this report and appendices may be obtained by telephoning Tammy Bailey at ASPE at (202) 401-7733 or may be ordered through the ASPE internet site: <www.aspe.os.dhs.gov>.

2. States included in the study were Georgia, Idaho, Massachusetts, Maine, Michigan, Missouri, New Hampshire, New York, Pennsylvania, Virginia, and Washington.

3. See, for example, O'Neil, C., & Nelsestuen, L. (1993). Distinguishing independent contractors from employees. *Florida Bar Journal*, 67(3): 47-51.

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The Cash and Counseling Demonstration: An Experiment in Consumer-Directed Personal Assistance Services

Pamela J. Doty, Ph.D.

The "Cash and Counseling" Demonstration/Evaluation is a large-scale public policy experiment designed to test the feasibility and assess the advantages and disadvantages of a consumer-directed approach to the financing and delivery of personal assistance services (PAS). The intent is to give Medicaid eligible persons with disabilities more choice about and control over the PAS they require. The experimental intervention is a cash benefit which allows recipients to make more of their own decisions about and arrangements for personal attendant and related personal assistance services. Classical experimental design methodology (i.e., random assignment of volunteer participants to treatment and control groups) will be employed to identify and evaluate the effects of the experimental intervention in a scientifically rigorous manner.

The Robert Wood Johnson Foundation (RWJF), a private charitable organization located in Princeton, New Jersey, has provided funding for development of the demonstration and for support of a National Program Office located at the University of Maryland Center on Aging. The National Program Office is responsible for overall project management and technical assistance to the participating states. The RWJF and the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services (OASPE/DHHS) are co-sponsors of the evaluation research component, which will be conducted under the oversight of the University of Maryland Center on Aging by Mathematica Policy Research. Kevin Mahoney, Ph.D.,

is the Project Director and Lori Simon-Rusinowitz, Ph.D., is the Deputy Project Director at the University of Maryland Center on Aging. Barbara Phillips, Ph.D., heads the evaluation team at Mathematica Policy Research.

Four states will participate as Cash and Counseling Demonstration sites: Arkansas, New Jersey, New York, and Florida. Each of these states has received close to \$500,000 in planning and implementation grants from the Robert Wood Johnson Foundation. The states were chosen through a competitive process in which 17 states submitted initial letters of intent. Ten states were invited to submit full proposals; from these the four finalists were selected.

In New York, Arkansas, and New Jersey, demonstration participants will be recruited from among those Medicaid clients whose services are covered under the personal care services optional benefit. In Florida, participants will be recruited from among Medicaid clients who are enrolled in the 1915(c) home and community-based long-term care waiver program. In all four states, both older (aged 65 and above) and younger adults (aged 18 to 64) with disabilities will be recruited to participate. In addition, in Florida only, there will be a third target group of demonstration participants comprised of children with disabilities and their parents.

Because the experimental intervention is a cash benefit and Medicaid law does not permit direct cash payments to clients, the state Medicaid programs participating in the Cash and Counseling Demonstration must obtain special "1115" research and demonstration waivers from the Health Care Financing Administration. Other federal agencies (the Social Security Administration and the Food Stamps Program run by the

Department of Agriculture) must also grant permission under their research and demonstration authority so that cash benefits in lieu of services will not be counted as income or assets for purposes of determining recipients' eligibility for income support (SSI) or Food Stamps.

Design of the Demonstration

In each of the four states, a fixed number of Medicaid-eligible individuals with long-term functional disabilities will be recruited to participate in the Cash and Counseling Demonstration. Although some participants are expected to be newly enrolled clients, the large majority will be persons who are already receiving Medicaid-financed PAS via the existing service delivery system. Because the evaluation incorporates a classical experimental design to test the effects of the new approach to service delivery, Cash and Counseling volunteers must be willing to accept random assignment to the treatment or control group. That is, they must agree to participate knowing that they will receive a cash payment in lieu of traditional services if assigned to the treatment group, but that only half of all participants will be assigned to the treatment group. The control group members will continue to be restricted to receiving the traditional service package which includes only attendant care in three of the states, available only

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from a limited number of authorized vendor agencies.

Cash and Counseling aims to maximize the degree of consumer direction available to Medicaid clients who use PAS services. In the traditional, professionally managed service delivery system, nurses and/or social workers assess clients' disabilities and associated care needs, then develop care plans. Typically, the professionals themselves have limited service options, with the result that care plans, though developed for particular individuals, tend to look very much alike, except that individuals with higher levels of disability receive larger amounts of the standard services. Professionals also arrange for the services in the care plan to be provided through one or more authorized provider agencies, which bill Medicaid for reimbursement after the services have been delivered. In Cash and Counseling, professionals will play a more limited role: they will continue to perform eligibility assessments and act as financial gatekeepers by establishing the amount of the cash benefit payment, based on an eligible client's severity of disability and related needs for assistance. However, the treatment group participants will be permitted to use their cash benefits to purchase a wide range of disability-related goods and services from the providers and suppliers they personally select—within the limits established by the fixed monthly dollar amount provided to each recipient. Thus, participants will not be restricted to purchasing personal attendant services but will also be able to buy transportation services, assistive technologies, home and vehicle modifications (such as lifts and ramps), adult day care, and respite services. The only restriction is that the services or products purchased must address disability-related needs; the cash payments may not be used as a general income supplement. Cash benefit recipients will meet with counselors who will help them develop their cash management plans and provide other advice. For example, a counselor might offer suggestions about how to recruit an attendant, including how to inter-

Cash and Counseling aims to maximize the degree of consumer direction available to Medicaid clients who use PAS services.

view and choose among several applicants for the job. Treatment group members will be required to account, periodically, for how they spend their cash benefits.

Cash benefit recipients will be permitted to carry over monies not spent from month to month, provided these funds are maintained in a special account. This will enable treatment group members to maintain emergency reserves for times when they may need more attendant hours than usual or to save toward a special purchase (such as an assistive device). In order to ensure public accountability, cash payment recipients will be required to document how they spend their funds and to keep receipts for purchases. Each state will develop its own monitoring plan. Consumers will be required to seek prior approval for unusual purchases. For example, one elderly consumer who participated in a focus group said that she might like to purchase a bicycle so that her grandchild could do grocery shopping and run errands for her, rather than having a paid attendant perform these tasks.

Although consumers will be permitted to pay their personal attendants directly, they will be required to comply and to document compliance with FICA and other tax requirements (which may include workers compensation and unemployment benefits in some states, depending on how much treatment group members pay per quarter or per year to individual employees). It is anticipated that many—perhaps most—Medicaid clients who are assigned to the treatment group and receive cash payments will choose

to access the services of a fiscal intermediary to withhold and pay taxes for the home care workers they hire.

Historical Background and Context

Personal assistance services encompass a range of types of human and technological assistance provided to persons with disabilities of any age who require help with basic activities of daily living (ADL's), including bathing, dressing, transferring, toileting, eating, and/or such instrumental activities of daily living (IADL's) such as housekeeping, meal preparation, shopping, laundry, money management, and medication management. For most persons with disabilities who require PAS, the core service is regular help with ADL and/or IADL tasks provided by a personal assistant (also referred to as a personal care aide or attendant). However, other products and services such as assistive devices, home modifications, home-delivered meals, adult day care, and handicapped transportation services may supplement or, in some instances, substitute for attendant care.

The primary source of funding for PAS for low income persons with disabilities is the Medicaid program. Coverage for PAS under state Medicaid programs is optional, but virtually every state provides access to PAS either through the Medicaid personal care services (PCS) benefit and/or one or more 1915© home and community-based services (HCBS) waiver programs. When PAS is financed through the PCS benefit, the *only* service offered is attendant care. When PAS is financed under an HCBS waiver, a broader menu of disability-related products and services is likely to be available, but it is often the service providers—including provider agencies specializing in "case management" services—who decide which services will be provided. Case managers also contract with home health and home care agencies, adult day care providers, meals-on-wheels providers, emergency alarm vendors, assistive technology suppliers, and others to provide the goods and services

specified in the care plan. Often, case managers must choose from a limited number and range of authorized vendors.

A number of state Medicaid programs (e.g., Oregon, Washington, Wisconsin, Michigan, Maryland, and California) already permit Medicaid clients to hire independent providers—individuals who are not employees of home health or home care agencies—to be their personal attendants. Some states permit clients to hire family members, friends, and neighbors to be their aides or attendants, although Medicaid funds may not be used to pay for attendants who are clients' spouses or the parents or legal guardians of clients who are minor children.

New York has made a "direct hire" option available for the past 15 years in New York City on a limited basis primarily for persons with disabilities under age 65 through an organization called *Concepts for Independence*. Under this model, Concepts for Independence serves as the employer of record for home care attendants hired directly by clients (Flanagan, 1997). Although Medicaid relates to Concepts for Independence as if it were the same as any licensed home care agency, it is actually a kind of client cooperative developed and run by persons with disabilities. Its founders were—and many current members still are—politically active in the disability rights and independent living movements. In 1995, New York enacted legislation that creates an entitlement for Medicaid home care attendant clients to "consumer-directed care"—that is, to be able to hire their own attendants directly. Because of this law, availability of consumer-directed services is slowly beginning to spread beyond New York City.

However, the majority of state Medicaid personal care services and 1915© waiver programs still require that attendant care be provided under the auspices of licensed home care agencies or Medicare/Medicaid certified home health agencies. Not infrequently, there is only one agency authorized to provide services in a given geographic area. Consumers who are dissatisfied

with the quality or reliability of the services they are receiving can ask the agency to send a different worker, but if consumers are dissatisfied with the agency management's response to complaints, there may be little recourse open to them if this is the only authorized provider agency in their area.

Disability rights advocates have long argued that persons with disabilities, who find themselves forced by circumstances of illness or accident to depend on others for help with routine daily activities, should be enabled and empowered to be as independent and autonomous as possible with regard to managing their own services. Advocates argue that public programs ought not mandate service delivery modes that cause persons with disabilities to be unnecessarily dependent on professional or bureaucratic authorities.

State and federal program administrators are becoming more aware that traditional modes of service delivery may unintentionally presume a high level of personal incompetency on the part of aged/disabled beneficiaries and foster excessive dependency in the name of consumer protection and/or public accountability. Moreover, program administrators also have a strong interest in achieving program economies. Often 30 to 40 percent of the hourly rates paid to home health and home care agencies go toward administrative overhead rather than toward wages and benefits paid to direct care workers (i.e., the personal attendants). Case management services are also expensive. An initial assessment and periodic reassessments of functional disability and need for services are required to determine program eligibility and authorize benefit amounts. However, program administrators are beginning to question—beyond the "gatekeeping" function—whether ongoing professional case-management (to develop a care plan, locate and arrange services, and monitor service providers) is universally required. Many consumers and/or family members could perform these ongoing service management tasks for themselves. Thus, encouraging consumer direction

could lower the cost of services by reducing administrative expenses. This would mean that the same clientele could obtain the same services more cost effectively, or, alternatively, a broader clientele could be served and/or more intensive services provided to those clients in need without increasing total program expenditures.

Theoretical Framework for the Evaluation

There is a growing body of research literature suggesting that although Medicaid clients who receive personal assistance services are generally satisfied with the services they receive, satisfaction increases in relation to the amount of personal choice and control that clients perceive themselves to have (Doty, Kasper, & Litvak, 1997). The degree of choice or control that clients are able to exercise can be conceptualized along several dimensions. These include:

- the ability to access advice as needed or desired—as opposed to being required to have a "case manager" who consults with the client in preparing the care plan but who holds the decision-making authority;
- the choice to receive attendant services through an agency or from an independent provider;
- the opportunity to participate in hiring, training, scheduling, and paying one's own attendants; and
- the freedom to purchase goods and services other than personal attendant care, especially assistive technologies and home and vehicle modifications that promote greater independence and autonomy by reducing the need for human assistance.

The potential benefits of Cash and Counseling include:

- promoting consumer choice and control over personal assistance services;
- increasing access to reliable, qualified home care workers willing to work flexible schedules, by permitting consumers to hire virtually anyone of their choosing, including family,

Some states permit clients to hire family members, friends, and neighbors to be their aides or attendants. . . .

friends, and neighbors if they so desire; and

- reducing administrative overhead and stretching scarce public dollars to cover more direct services.

Accordingly, the project's goals are to:

- test the feasibility of a cash payment alternative to traditional agency provided services and to determine what percentage of Medicaid clients, with what characteristics (e.g., younger versus older, more versus less severely disabled) are potentially interested in an optional cash benefit;

- to find out whether consumers who receive cash benefits are able to manage those benefits without experiencing too much difficulty and what supportive services they may want or require;

- to explore whether and to what extent consumers' use of services differs when they have cash and make their own choices rather than having services arranged for them by home care agency employed nurses or by case managers employed or under contract to state/county government; and

- to measure the differential effects, if any, of receiving cash benefits as contrasted with traditional services on consumer and family caregiver satisfaction, public program costs, and health outcomes.

Planning and Implementation Schedule for the Demonstration

The Cash and Counseling Demonstration/Evaluation is being carried out in three phases:

- **Phase I** (from October 1, 1995 to October 1, 1996) has been completed. It

involved the selection of the participating states and the evaluation contractor.

- **Phase II** (from October 1, 1996 through August 1998) is nearing completion. It involves:

- the creation of detailed demonstration and evaluation designs for each state,

- conducting focus groups and consumer preference studies to estimate consumer take-up rates and to aid the development of an outreach/marketing plan to recruit participants,

- application for and approval of HCFA "1115" research and demonstration waivers, and

- coordination with other federal agencies to ensure that Cash and Counseling Demonstration participants are exempted from negative impacts of the cash benefit on eligibility for other federal programs, such as Food Stamps or SSI.

- **Phase III** (anticipated to begin in September 1998) will involve:

- enrollment of consumers in the demonstration (open enrollment for 1 year), including personalized outreach to potential participants to inform them of their eligibility to participate,

- baseline interviews with and randomization of participants to treatment and control groups,

- interviews with treatment group members to learn of their initial experiences in managing the cash benefit approximately 3 to 4 months after enrollment,

- followup interviews with treatment and control group members and supplementary interviews with family caregivers, and paid workers at 8 months,


- interviews with state officials and other stake holders for an implementation process report,

- tracking of various cost and health outcome measures through claims and other administrative data sources through 1 year following enrollment for each participant, and

- analysis of the data and the writing and dissemination of a final report.

Medicaid clients who participate in the Cash and Counseling Demonstration will be followed for purposes of the evaluation for 1 year; however, treatment group members may continue to

receive cash benefits in lieu of traditional services for at least 1 additional year.

For further information about the Cash and Counseling Demonstration, you may contact the federal project officer: Pamela Doty, Ph.D., Senior Policy Analyst, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, Room 424E, 200 Independence Avenue, S.W., Washington, D.C., 20201. (Telephone: (202) 690-6172, E-mail: PDoty@OSASPE.DHHS.GOV). 

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Virginia's Consumer-Directed Personal Assistance Services Program: *A History and Evaluation*

Over the course of the last decade, Virginia has developed a model personal assistance services program that stresses consumer involvement and consumer direction of services. Administered by the Virginia Department of Rehabilitative Services (VDRS), this program was recently the focus of a 3-year outcomes evaluation conducted by the National Rehabilitation Hospital Research Center (NRH-RC). In the following sections, the history of Virginia's consumer-directed personal assistance program will be detailed, as will the findings of NRH-RC's evaluation. The policy implications of the evaluation's findings will then be discussed, in the context of current policy initiatives.

*Phillip Beatty, MA
Martha Adams
Bonnie O'Day, Ph.D.*

Virginia's consumer-directed personal assistance services (CD-PAS) program has a long history of consumer involvement. Since its inception nearly a decade ago, it has focused on increasing the well-being and independence of Virginia's consumers with disabilities. A brief history of the program follows.

The PAS Project

The Virginians with Disabilities Act, which requires that state funded programs and facilities adhere to the federal legislation similar to Section 504 of the Rehabilitation Act, was passed by the Virginia General Assembly in 1986. Independent living advocates argued that these laws, while an important step, neglected to address the needs of consumers who could not access buildings, transportation, or programs without adequate personal assistance services. As a result of these concerns, a cross-disability coalition obtained funding through the state's Developmental Disabilities Council to study the status of attendant services in Virginia and other states, identify policy issues that posed barriers to independence, and design a pilot program to address those problems. This PAS project was directed by an advisory board which included several PAS users and advocates, directors of independent living centers, and state agency representatives.

The first goals of this PAS project were to determine the level of need for personal assistance services and to un-

derstand the everyday concerns and priorities of people with disabilities. In order to obtain this information, 12 widely publicized public hearings were held across the state. A toll-free telephone number was made available for those who wanted to participate in the project but were unable to attend the public hearings. In addition, home visits were conducted to ensure the participation of consumers who were unable to leave home, talk on the phone, or participate in any other way.

Institutionalization concerns. The most commonly voiced consumer concern was the unwillingness to live in a nursing home, coupled with the realization that the available attendant services would not permit them to live at home in the community for an extended period of time. It was found that family members providing assistance were frequently unable either physically or financially to provide the level of help needed and other volunteer sources were unpredictable. For many, the choice to live at home without adequate services had seriously jeopardized their health to the extent that employment or any other independent living activity was not a consideration.

Medicaid concerns. It was also found that the fear of nursing home placement was consistent among recipients of Medicaid Waiver programs, even

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A large number of people with disabilities explained that their independence was impeded by barriers within the home.

though these services were established solely to prevent nursing home placement. This fear was linked to the inability to receive adequate services at home, which was often directly tied to the availability of staff in licensed home care agencies—the only providers eligible through Virginia's Medicaid program. Consequently, assistance was limited to a few days per week, provided only during normal working hours, or unpredictable, depending upon the number of calls an aide could complete each day. Some areas of the state had no providers at all, including the Northern Virginia/Washington, D.C., metropolitan area where agencies would not accept the Medicaid reimbursement rate. Added to this problem were restrictions placed on home care aides that prevented them from doing any bowel or bladder care or assisting the recipient outside the home.

Employment concerns. People with disabilities were concerned that they would lose access to personal assistance through Medicaid waivers if they were to become employed, based on Medicaid eligibility rules stating that recipients can receive no more than the current Supplemental Security Income (SSI) rate. Those individuals who were employed felt that they could not maintain their employment without more consistent assistance. These consumers typically relied on family or other unpaid assistance, and tended to experience a high absentee rate and tardiness at work when assistance was not available. Others were paying for some help but had very little income left to pay rent, utilities, transportation costs, or other routine expenses. Consequently, employment could not be sustained

unless predictable volunteer help was available or their earnings were sufficient to pay for additional services privately. In most cases, neither of these options was realistic.

Concern with environmental barriers. A large number of people with disabilities explained that their independence was impeded by barriers within the home. In many instances, the lack of independence and the level of assistance needed was directly tied to the consumer's inability to get in and out of the bathroom or to leave the home. The inability to lock the door or use the phone independently posed substantial levels of fear when others were not available. Although home modifications or adaptive devices could alleviate these problems, consumers did not know about them and/or could not afford them.

The Virginia Consumer-Directed PAS Program

Virginia's consumer-directed personal assistance services (CD-PAS) program, administered by the Virginia Department of Rehabilitative Services (VDRS), began providing services to 18 people with disabilities in 1990. As of the first quarter of calendar year 1998, 320 consumers are participating in the program. The characteristics of the CD-PAS program were developed specifically to address the concerns of individuals in the PAS pilot project outlined in the previous section. Specific characteristics of Virginia's program will be outlined in the following paragraphs.

Needs assessment. VDRS contracts with centers for independent living (CIL's) to conduct needs-assessments of individuals requesting services through the CD-PAS program. The CIL's PAS coordinator determines the type of assistance required during a home visit. A standard allotment of time is awarded for most tasks, while other activities that are more individually-based, such as range of motion exercises or help with school activities, are calculated separately. The assessment also includes an evaluation of the home, school, or work area to deter-

mine whether environmental barriers create the need for additional assistance. If home modifications or adaptive devices could enhance the delivery of personal assistance, either through reduced cost or increased consumer safety, these costs may be eligible for program funding. The consumer is also assisted in identifying other funding sources for modification or devices.

Consumer management of assistants. Once the weekly hours of PAS required has been determined, the consumer may schedule the hours throughout the week as they are needed. Recipients recruit, select, schedule, and manage one or more assistants of their choice. Assistants may help with any tasks identified in the needs assessment and listed on a contract negotiated between the consumer and personal assistant. Personal assistants are not required to present any certification or licensure in order to work, but must verify to the consumer that they are legally permitted to work in the United States. The quality of work performed is rated solely by the consumer.

Income and resources of the PAS recipient are considered when determining the cost of the service. A copayment is calculated based on both consumer income and expenses. Allowable deductions include disability-related expenses, mandatory payroll withholding, dependents allowance, private health insurance premiums, and child care expenses for working parents.

Support services. These are provided by CIL's. Services include preliminary assessment and development of consumers' independent-living skills. CIL's provide training in personal assistant management, which includes developing job descriptions based on personal preferences and needs, interviewing tips, and communication skills. Centers also do periodic recruitment of potential assistants and offer an orientation in typical needs of people with disabilities and the independent living focus of CD-PAS. This recruitment and training of potential assistants is conducted primarily by users of personal assistance. CIL's compile a registry of potential assistants which is then made

available to any consumer upon request.

In sum, the Virginia CD-PAS program incorporates all of the following characteristics of the pure independent living model, as outlined in *Attending to America* (Litvak, 1987):

- No medical supervision is required.
- Services offered include personal maintenance and hygiene, mobility, and household assistance.
- The maximum service limit exceeds 20 hours per week.
- Service is available 24 hours a day, 7 days a week.
- The income limit is greater than 150 percent of the poverty level.
- Individual providers can be utilized by the consumer.
- The consumer hires and fires the attendant.
- The consumer trains the attendant.
- The consumer participates in deciding on the number of hours and type of service he or she requires.

Evaluation of Virginia's Consumer-Directed PAS Program

Because the Virginia consumer-directed PAS program incorporates all of the above listed characteristics which are highly valued by the independent living movement, it is a particularly useful site to gage the extent to which these values are translated into positive outcomes and potential policy. The National Rehabilitation Hospital Research Center (NRH-RC), with a 3-year grant (1994-1997) from the National Institute on Disability and Rehabilitation Research (NIDRR), conducted a series of consumer surveys to determine the effect of Virginia's CD-PAS program on a wide variety of consumer outcomes.¹

Study design. NRH-RC's evaluation of the Virginia CD-PAS program was designed as a quasi-experimental comparison of individuals with disabilities receiving consumer-directed PAS and a similar group of individuals on the waiting list to receive services. The study consisted of four rounds of mailed questionnaires, administered

approximately every 6 months beginning November 1994. Findings from the first round of questionnaires, in which 62 CD-PAS recipients and 62 people on the waiting list responded, will be highlighted in this article. While the study team originally believed the two groups to be similar in most regards, it was found that there were important differences which were related to the criteria for moving people off the waiting list and into the program.

Individuals meeting the eligibility criteria to receive consumer-directed PAS are removed from the waiting list and entered into the CD-PAS program based on certain risk-based criteria. Individuals who are in a nursing home or are at risk of being placed in a nursing home are given priority placement in the CD-PAS program, as are people who are experiencing acute health problems due to the need for nonmedical assistance services. As a result of these risk-based placement criteria, the sample of people receiving services reported having more severe disabilities and poorer health than their waiting list counterparts. These differences in health and functional status were kept in mind and controlled for when analyzing the relationship between receipt of CD-PAS and a wide variety of outcomes. There were no differences between the PAS and waiting list groups in terms of common sociodemographic variables such as race, sex, education, marital status, or age.

Outcomes

The NRH-RC evaluation team was interested in determining the relationship between the receipt of CD-PAS and a variety of outcomes categories through a comparison of the PAS and waiting list groups. The outcomes categories of interest were: healthcare utilization patterns; control over one's life; employment and productivity; and satisfaction with PAS services.

Healthcare utilization. Those receiving consumer-directed PAS had consistently higher rates of general preventive healthcare utilization compared to those on the waiting list. In nearly

every 6-month period measured in each of the four waves, a greater percentage of PAS recipients than waiting list respondents reported having a general medical examination, a cholesterol check, and a blood pressure check. Similarly, females in the PAS group were more likely to report OB/Gyn visits, pap smears, and breast exams over the course of a 6-month period, in nearly every wave.

Further comparisons indicated lower rates of utilization among the PAS group for doctor visits due to a medical

Researchers have shown CD-PAS to be significantly less costly on a per capita basis than nursing home placement, or than agency sponsored models of personal assistance.

condition, emergency room visits, hospital days, skilled nursing facility days, and visits from home health providers. The only healthcare utilization category where PAS respondents had higher rates than those on the waiting list was for days in a rehabilitation facility.

Control over one's life. Control over one's life was measured by the 10-item control subscale of the *Personal Independence Profile*, which was developed by Margaret Nosek and her colleagues at Independent Living Research Utilization. This scale asks people to rate their feelings of control over material comforts, participation in active recreation, health and personal safety, relationships, socializing, work, and other areas of life. After controlling for the fact that the PAS group was more severely disabled and in poorer health than those on the waiting list, it was found that those receiving CD-PAS had significantly greater feelings of control over their lives than those not receiving consumer-directed services. These find-

ings regarding control over one's life is most likely related to the finding that the group of people receiving CD-PAS was consistently more likely to report living in their own home, apartment, or university dormitory, relative to those on the waiting list.

Employment and productivity. Employment rates were found to be consistently higher for those in the PAS group than for those on the waiting list. In the first round of the survey, 22 percent of CD-PAS recipients were employed, compared to 11 percent of those on the waiting list, despite the fact that those in the PAS group tended to have more severe disabilities and to be in poorer health. After controlling for these differences in disability level and health status, this difference in employment rates was statistically significant.

Productivity was measured more generally by the Occupation subscale of the *Craig Handicap Assessment & Reporting Technique* (CHART), developed by Gale Whiteneck and his colleagues at Craig Hospital in Englewood, Colorado. This scale is a weighted summary of weekly hours spent in activities such as paid employment, school, homemaking, home maintenance, volunteer work, recreational activities, and self-improvement activity. The receipt of consumer-directed PAS was significantly associated with greater productivity as measured by the CHART. This is the central finding of an article recently published by the evaluation team in the *Journal of Rehabilitation Outcomes Measurement*, (Richmond, Beatty, Tepper, & DeJong, 1997).

Satisfaction with PAS services. Consumer-directed PAS recipients scored consistently higher on the *Personal Assistance Satisfaction Index* (PASI), than did their waiting list counterparts who were receiving PAS that was not consumer-directed. The PASI is a 16-item battery developed by Margaret Nosek and her colleagues at Independent Living Research Utilization to measure satisfaction with all aspects of personal assistance services. The comparison group for this satisfaction analysis were those on the waiting list receiving PAS through Medicaid waivers or through

the expenditure of personal funds. On 14 of the 16 individual items, CD-PAS recipients were more likely to report being highly satisfied than the comparison group. The greatest differences in satisfaction were for those items measuring control over choice of assistants, control of assistants' work schedule, authority to direct personal assistants, and flexibility of services. For more detailed information on this association between the receipt of CD-PAS and satisfaction with services, please refer to an article recently published by the evaluation team in the *Archives of Physical Medicine and Rehabilitation* (Beatty, Richmond, Tepper, & DeJong, 1998).

In sum, the results of the NRH-RC evaluation of Virginia's CD-PAS program suggest that consumer-direction in the delivery of personal assistance services is related to positive outcomes. Increased utilization of preventive healthcare, increased feelings of control over life, increased rates of employment and productivity, and relatively high rates of satisfaction were found to be positively associated with the receipt of consumer-directed services. Virginia's CD-PAS program was developed over an extensive period of time, throughout which the needs and priorities of individuals with disabilities was the central and driving concern. By prioritizing consumer involvement throughout the development of the program, Virginia has created a program that not only serves to minimize the risk of institutionalization and deteriorating health, but also promotes the independence and well-being of its consumers.

Translating Virginia's Experience with CD-PAS Into Policy

The passage of federal personal assistance legislation appears to be the highest priority for national disability organizations, including the National Council on Independent Living (NCIL) and Americans Disabled for Attendant Programs Today (ADAPT). The experience of the Virginia CD-PAS program may help to inform the efforts of these groups and legislators as they work toward the goal of a federal PAS program.

Employment rates were found to be consistently higher for those in the PAS group than for those on the waiting list.


NCIL and ADAPT have successfully advocated for the introduction of consumer-controlled PAS legislation in both the House (HR 2020, sponsored by Gingrich, R/GA), and the Senate (S. 879, sponsored by Feingold, R/WI) of the United States. A hearing on HR 2020 was held before a packed audience of disability advocates and healthcare providers in March 1998. At this writing, the Senate bill has not been scheduled for a hearing.

The Senate bill establishes a new and very detailed program of Home and Community Based Services for people with ADL limitations, or those who need in-home support due to mental disabilities. The House bill is more general in nature, and limited to those who need nursing home services or who would be eligible for placement in an Intermediate Care Facility for the Mentally Retarded (ICF-MR). Because the House proposal is an additional Medicaid service intended to shift Medicaid funds away from nursing home placement towards home and community-based services, it would serve only those who are Medicaid eligible—in effect, only those who receive SSI or who are very poor.

The research findings cited in this article will enable advocates to go beyond statements of need and personal anecdotes to provide valuable empirical evidence when advocating for PAS legislation. Evidence from the Virginia CD-PAS study can be used to set forth a model to "flesh out" the House legislation. The Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, has been charged with recommending a cost effective, efficient PAS model on which to base Administration proposals. Addi-

tionally, several states, including Arkansas and Iowa, are considering the implementation of various PAS models to decrease institutionalization and home care costs. Statistically sound and valid research indicating that consumer-controlled PAS users experienced higher levels of satisfaction, lived more independently and autonomously, utilized preventive healthcare services more consistently, and had higher employment rates will be invaluable as these evaluations take place.

Researchers have shown CD-PAS to be significantly less costly on a per capita basis than nursing home placement, or than agency sponsored models of personal assistance (Prince, Manley, Whiteneck, 1993). However, if Congress is to seriously consider comprehensive PAS legislation, meaningful estimates of the aggregate costs of implementing such legislation must be developed. These estimates must not only consider costs of community-based care for individuals who would avoid nursing home placement, but the "induced demand" of those who would substitute paid PAS for informal or unpaid services. While additional research

that compares the costs of various PAS models is much needed, findings from the evaluation of Virginia's CD-PAS program suggest that at least some cost savings will be realized, based upon the increased employment and productivity and increased utilization of preventive healthcare services among consumers of consumer-directed personal assistance services. 

Note

1. NIDRR Project No. H133G40070: *The Effect of Consumer-Directed Personal Assistance on the Outcomes of Persons with Physical Disabilities.*

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AMERICAN REHABILITATION

Summer-Autumn 1998

Personal Assistance Services
Part 1 of 2



If you find in **American Rehabilitation** the kind of material that informs or that is useful to you in some way, a colleague who does not receive the magazine may also profit by it. If you know such a person, fill out the blank below and send it to Editor, **American Rehabilitation**, Room 3033, 330 C Street, S.W., Washington, DC 20202-2531. We will be happy to send your friend a sample copy of the magazine.

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NEW PUBLICATIONS AND FILMS

A Brief Introduction to Social Role Valorization. A High-Order Concept for Addressing the Plight of Societally Devalued People, and for Structuring Human Services. 3rd Edition.

Wolf Wolfensberger. *Syracuse University Training Institute, 805 South Crouse Ave., Syracuse, NY 13244-2280. Softcover, 139 pages, \$14.00.*

This monograph addresses the following topics:

- the universal dynamics of social devaluation;
- social devaluation and socially devalued classes in contemporary Western societies;
- a brief review of the common hurtful things that get done to societally devalued people as a consequence of their devaluation;
- the dynamics of role expectancies;
- how personal experience, role expectancies, and environmental conditions all interact to generate social judgments about the value of people;
- the power of social roles in determining both people's behavior and their place in society;
- the complex relationship between deformities, impairments, and other afflictions, and the holding of valued or devalued social roles;
- the benefits of filling valued social roles; and others.

Getting Into a Residency. A Guide for Medical Students. Third edition.

Kenneth V. Iserson, M.D. *Routledge, 29 West 35 Street, New York, NY 10001. Softcover, 433 pages, \$28.95.*

A step-by-step guide through the process of selecting a medical specialty and obtaining a residency position. Packed with tips and practical information, this book provides invaluable

information about all the medical specialties, including the difficulty of obtaining a position and the number of available slots.

Clinical Tropical Medicine.

G.O. Cowan and B.J. Heap. *University of California Press, 2120 Berkeley Way, Berkeley, CA 94720. Softcover, 314 pages, \$42.50.*

This manual covers the essential aspects of clinical tropical medicine by outlining the nature, transmission, epidemiology, and management of various diseases and infections associated with tropical climes. It is intended as a guide for doctors specializing or training in tropical medicine and infectious diseases, and for physicians taking up posts in tropical countries. It should also be useful as a course textbook for undergraduate and postgraduate qualifications in Tropical Medicine and Hygiene.

Foundations of Rehabilitation Teaching With Persons Who Are Blind or Visually Impaired.

Paul E. Ponchillia and Susan V. Ponchillia. *AFB Press, American Foundation for the Blind, 11 Penn Plaza, Suite 300, New York, NY 10001. Hardcover, 413 pages, \$56.95.*

Intended to assist in the preparation of rehabilitation teachers for work with people who are blind, this book draws upon the knowledge base accumulated since the beginning of the profession. It is organized in five parts. Part 1 provides an overview of the profession and other background information, including a history of rehabilitation teaching. Part 2 provides the reader with the foundation needed for evaluation, planning, and delivery of services. Parts 3 through 5 correspond to the essential function of the rehabilitation teacher: in-

struction in the areas of adaptive communication, activities of daily living, and management skills.

The Edgar Cayce Way of Overcoming Multiple Sclerosis: Vibratory Medicine.

Dr. Dudley Delaney. *Meridian Publishers, P.O. Box 7987, Hampton, VA 23666. Tel: (757) 850-2963. Softcover, 120 pages, \$10.95, plus \$3.50 for shipping and handling.*

Multiple sclerosis is a chronic, incurable disease of the brain and spinal cord that can gradually result in total disability. The cause is unknown, and it currently afflicts over one million persons worldwide.

In the summer of 1991, it struck Dr. Dudley Delaney, a now retired chiropractor, massage therapist, and registered nurse. His symptoms included numbness, blurred vision, difficulty swallowing, tremors, muscle spasms, depression, fatigue, failing memory, slurred speech, and bladder dysfunction. In the fall of 1991, Dr. Delaney began using an alternative medicine treatment suggested by the late Edgar Cayce, a man widely regarded as the Father of Holistic Medicine. It involved massage, close attention to diet, and low levels of electricity. Within 2 years, he was symptom-free.

This book, which was written as a result of his experience, contains many recommendations potentially helpful in combating this perplexing malady.

Serving Individuals with Diabetes who are Blind or Visually Impaired: A Resource Guide for Vocational Rehabilitation Counselors.

The National Federation of the Blind, in collaboration with The Rehabilitation Research

and Training Center on Blindness and Low Vision. Softcover, 225 pages, \$25.00. Also available in large print, Braille, audio cassette, or on computer diskette for \$25.00

This publication contains a wide variety of resources on various diabetes publications, medications and appliances, as well as Internet list servers and web sites.

Children with Disabilities. Fourth Edition.

Mark L. Bradshaw, M.D., editor. Paul H. Brooks Publishing Co., The Maple Press Distribution Center, I-83 Industrial Park, P.O. Box 15100, York, PA 17405. Hardcover, 992 pages, \$49.95.

Included in this edition are new chapters on substance abuse, AIDS, Down's syndrome, Fragile X syndrome, behavior management, transitions to adulthood, and medical care in the 21st century, as well as current information on the causes of many conditions that can lead to developmental disabilities. A handy new appendix describes the properties and uses of a wide variety of medications.

Designing and Delivering Quality Assistive Technology Services.

CARE, 4891 E. Grant Road, Tucson, AZ 85712. Telephone: Voice/TDD, (520) 325-1044; FAX, (520) 318-1129. [E-mail: <http://www.carf.org>] Softcover 28 pages, \$20.00 plus \$7.00 shipping and handling. Orders to Canadian destinations should add \$5.00, and orders to overseas addresses should add \$25.00. Payment must be in U.S. dollars.

Designing and Delivering Quality Assistive Technology Services emphasizes the importance of using assistive technology to aid persons with disabilities in using and developing their skills, achieving success in employment, increasing productivity, enhancing self-esteem, supporting functional skills in activities of daily living, and gaining more options for independence.

The monograph covers relevant legislation, such as the 1988 *Technology-Related Assistance for Individuals with Disabilities Act*, the principles of assistive

technology, and the steps to developing quality assistive technology services.

The contents of the monograph apply to all rehabilitation fields and are designed to assist organizations preparing for CARF surveys in *Employment Assistive Technology Services* or *Community Assistive Technology Services*—two new service areas available for CARF accreditation beginning July 1, 1998.

Nothing About Us Without Us: Disability Oppression and Empowerment.

James I. Charlton. University of California Press, 2120 Berkeley Way, Berkeley, CA 94720. Hardcover, 247 pages, \$27.50.

A study of the global oppression of people with disabilities and the international movement that has recently emerged to resist it, this book provides a theoretical overview of disability oppression that shows its similarities to, and differences from, racism, sexism, and colonialism.

Long-Term Care. Federal, State, and Private Options for the Future.

Raymond C. O'Brien and Michael T. Flannery, The Haworth Press, Inc., 10 Alice St., Binghamton, NY 13904-1580. Hardcover, 290 pages, \$49.95; softcover, \$24.95.

Long-Term Care presents the authors' views on how society might contain healthcare costs, offer fair and competent treatment to the poor, the middle class, and the wealthy, and prevent the collapse of the Medicare and Medicaid programs.

A Slant of Sun: One Child's Courage.

Beth Kephart. W.W. Norton & Company, Inc., 500 Fifth Avenue, New York, NY 10110. Tel: (212) 354-5500. FAX: (212) 869-0856. Hardcover, 249 pages, \$23.00

The author shares the painful and inspiring experience of loving a child whose "special needs" bring tremendous frustration and incalculable rewards. Diagnosed with "pervasive developmental disorder not otherwise specified," the author's son, Jeremy, slowly emerges from a world of obses-

sive play rituals, atypical language constructions, endless pacing, and lonely frustrations, with the help of passionate parental involvement and the kindness of a few open hearts.

The Mind's Past.

Michael S. Gazzaniga. University of California Press, 2120 Berkeley Way, Berkeley, CA 94720. Hardcover, 216 pages, \$22.50.

Why does the human brain insist on interpreting the world and constructing a narrative? In this book, the author shows how our mind and brain accomplish the amazing feat of constructing our past—a process clearly fraught with errors of perception, memory, and judgment. By showing that the specific systems built into our brain do their work automatically and largely outside of our conscious awareness. The author calls into question our everyday notions of self and reality. The implications of his ideas reach deeply into the nature of perception and memory, the profundity of human instinct, and ways we construct who we are and how we fit into the world around us.

The author explains how the mind interprets data the brain has already processed, making "us" the last to know. He shows how what "we" see is frequently an illusion and not at all what our brain is perceiving. False memories become a part of our experience; autobiography is fiction.

The Pediatric Spine: Principles and Practice. Volumes 1 and 2.

Stuart L. Weinstein, editor. Raven Press, 1185 Avenue of the Americas, New York, NY 10036. Tel: (212) 930-9500. FAX: (212) 869-3495. Two volumes. Hardcover, 1,959 pages, \$285.00 (subject to change).

These volumes bring together international experts from several disciplines to provide a definitive reference text for the healthcare professional interested in problems related to the pediatric spine. They provide the reader with an indepth study of the disorders of the pediatric spine and related conditions.

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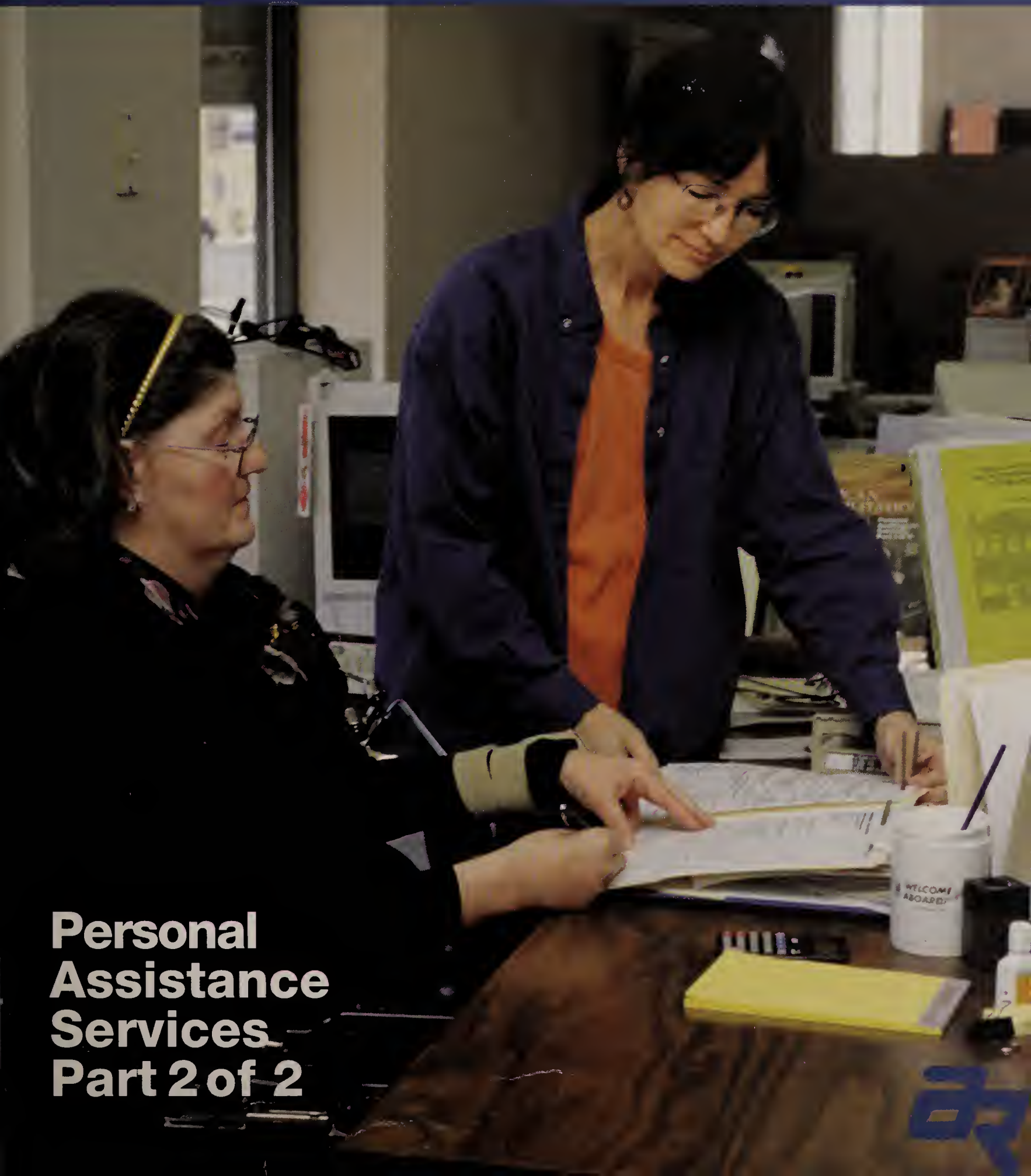
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AMERICAN WINTER 1998 REHABILITATION



**Personal
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Part 2 of 2**



A Summary of the Rehabilitation Act Amendments of 1998



Fredric K. Schroeder

*Commissioner,
Rehabilitation Services Administration*

On Friday, August 7, 1998, President Clinton signed into law the Workforce Investment Act, which includes the 1998 Amendments to the Rehabilitation Act (the Act) and reauthorizes that Act for 5 years. The 1998 Amendments will greatly strengthen the public rehabilitation program by streamlining administrative procedures, expanding options for consumer choice, improving due process provisions, and increasing opportunities for consumers to obtain high quality employment. The Amendments also link the vocational rehabilitation (VR) program to a state's workforce development system.

Expanding Consumer Choice. The Amendments expand options for consumer choice in several ways. State VR agencies, in consultation with their State Rehabilitation Councils, are required to develop and implement policies and procedures to afford opportunities for applicants for services and eligible individuals to exercise informed choice throughout the rehabilitation process. The agencies must also provide information and the necessary support services to assist applicants

and eligible individuals in making informed choices. These requirements reflect the policy that individuals with disabilities are to be full and active partners in their rehabilitation programming through the exercise of informed choices with respect to assessments for determining eligibility and VR needs and in the selection of their employment goals, services, and service providers.

The Individualized Plan for Employment (IPE) is a written plan that identifies the employment goal, services, vendors, and other information related to an individual's vocational rehabilitation. The 1998 Amendments changed the name of the plan from the Individualized Written Rehabilitation Program to the IPE in order to emphasize the employment focus of the VR program. The IPE provisions in the 1998 Amendments expand upon the role of the eligible individual as a collaborating partner in the development, implementation, monitoring, and evaluation of his or her own plan. Eligible individuals (or their representatives) now have the option of developing their own IPE or requesting assistance in developing their plan from a qualified VR counselor.

Other new statutory requirements enable eligible individuals to exercise informed choice in the selection of their employment goal, services, service providers, and the methods used to procure their services. The Act also requires that services under an IPE be provided in the most integrated setting that is both appropriate to the service being provided and also reflects the informed choice of the individual.

Streamlining Administrative Procedures. The Amendments streamline the provisions for the state plan for VR services by reducing the former 36 state plan provisions to 24, and by limiting the circumstances under which a new

State plan or plan amendment must be submitted to the Rehabilitation Services Administration. The amended Act now provides states with flexibility in locating the agency that the state designates to administer the VR program and retains the organizational requirement that the agency include a VR unit whenever the designated state agency is not primarily concerned with vocational rehabilitation, or vocational and other rehabilitation of individuals with disabilities.

The Amendments also reduce the burden on states by eliminating requirements for a strategic plan; however, the requirement that a portion of the Title I formula grant funds for the VR program be reserved to support the development of innovative approaches to expanding and improving VR services, particularly to individuals with the most significant disabilities was retained.

Previously, the 1992 Amendments to the Act included the provision that all individuals with disabilities were presumed to benefit from VR services in terms of an employment outcome unless the state VR agency demonstrated by clear and convincing evidence that the individual was incapable of doing so. Following the 1992 Amendments, the national eligibility rate in the VR program rose from 56.5 percent in 1992 to 76.5 percent in 1996.

The 1998 amendments further simplify and streamline eligibility determinations by establishing presumed eligibility for disabled individuals who are recipients of Supplemental Security Income (SSI) or beneficiaries of Social Security Disability Insurance (SSDI) payments. While presumed eligibility does not establish an entitlement to VR services for SSI recipients and SSDI beneficiaries, the provision recognizes that these individuals have already been determined, pursuant to the stringent

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The weakest ink is better than the strongest memory.

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Cover Photo : Dorothy Pat Fairchild, an employee of the Endependence Center of Northern Virginia (ECNV), goes through case files with Shelley Wade, a volunteer personal assistant for the center. The arm support on Ms. Fairchild's arm helps with her reach and enables her to eat independently. To her left is Ms. Fairchild's voice activated computer. (Photo by Frank Romano)

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Manuscript and article suggestions are welcome. Write to: Editor, *American Rehabilitation*, Rehabilitation Services Administration, Room 3033 MES, 330 C Street, S.W., Washington, DC 20202-2531. Telephone: (202) 205-8296. FAX: (202) 205-9874.

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Prospects for a National Personal Assistance Services Program:

Enhancing Choice for People With Disabilities

Andrew I. Batavia, J.D., M.S.

This article considers the current prospects for enacting a national personal assistance services program offering services under the independent living model in this country. Many people with disabilities prefer the independent living model because, by empowering them to recruit, select, manage, and direct their own personal assistants, it offers the greatest potential to control their lives and live independently in their communities. The prospects for establishing a national program have been affected in recent years by several developments: a) further acceptance of the independent living philosophy in our society; b) several recent proposals for a national personal assistance services program; c) expansion of state Medicaid waivers allowing recipients with disabilities to receive personal assistance services in their communities; d) enhanced interest in the independent living model among the older disabled population; and e) a relative decrease in the political power of the nursing home and home health industries. This article considers these developments, concluding that they increase the political viability of a national program. It further concludes that beneficiaries should be able to receive their personal assistance services under their preferred model, and that there are important policy tradeoffs in determining whether services should be provided in-kind, in cash, or in cash equivalent.

Several years ago, my colleagues and I recommended the establishment of a national personal assistance services program organized under the independent living model for people with disabilities (Batavia, DeJong, & McKnew, 1991). Under this model, the disabled person is considered a self-directed active recipient of services who recruits, selects, trains, manages, and directs his or her own "personal assistant." This model may be contrasted with the traditional informal support model, in which an unpaid family member or friend provides such services, and with the medical model, in which the assistant is a trained healthcare worker supervised by other healthcare professionals. We argued that the independent living model is most consistent with the goals of the majority of people with disabilities to control their lives, and to live as independently and productively as possible in their communities.

We further contended that a national program, or at least a coordinated national policy, is necessary because without it, each state would be discouraged from expanding access to personal assistance services for fear that thousands of people with disabilities would decide to move to their state to obtain the generous benefits. Conversely, we were concerned that some states might actually reduce their benefits in an ef-

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fort to dissuade people with disabilities from being in their programs. These concerns about a "race to the bottom," in conjunction with the horizontal equity concern that people with identical disabilities had vastly different levels of access to personal assistance based upon geographic location, suggested a strong case for a national program or coordinated policy (Batavia, 1993). Others have similarly recommended the establishment of a national program, and some have also made specific proposals (Litvak, Zukas, & Heumann, 1987; Nosek, 1991).

Since that time, several important developments have occurred that affect the feasibility of a national program. In this article, I will consider these developments and how they are likely to affect the viability of establishing a national program. I will then consider two major policy issues that must be considered in establishing a national program: 1) whether to provide personal assistance services in-kind (i.e., through the direct provision of services) or by providing the individual with a disability cash or a cash equivalent (such as a voucher, medical savings account, or tax credit) and 2) whether, in addition to the independent living model, services should be offered under other models, such as the medical model.

Further Acceptance of the Independent Living Philosophy in Our Society.

Thirty years ago, the notion that a large proportion of people with "severe disabilities" could live independently in the homes and communities of their own choosing was, for the most part, wishful thinking. Although a relatively small percentage of these individuals did achieve such independence, they were primarily individuals with access to significant financial resources. They were the exception to the rule; the vast majority of people with major disabilities lived in institutions or in the homes of family members who took care of them without any compensa-

tion. The amount of autonomy and freedom that most individuals with disabilities were able to exercise depended in large part on the amount of assistance available from institution employees, volunteers, and family members. Many were—and many continue

The majority of Americans now actually support the independent living goals of people with disabilities.

to be—severely limited in their freedom (Nosek, 1991).

The independent living movement was established in the early 1970's largely by people with disabilities in response to these circumstances (DeJong, 1979). The fundamental premise of the movement was that barriers to independent living must be removed so that people with disabilities could live independently and productively in their communities. One of the cornerstone policy issues of the movement was, and continues to be, access to home and community-based personal assistance services provided under the independent living model (DeJong & Wenker, 1983). Without such access, individuals with substantial functional limitations who do not have substantial financial resources either are not able to live in the communities as they choose or must rely upon the charity or altruism of others in order to do so. Access to personal assistance is also key to maintaining good health for many people with disabilities (DeJong, Batavia, & Griss, 1989; Nosek, 1993).

Thirty years later, we are in the midst of what may be described as a paradigm shift concerning the societal expectations of people with disabilities. Although many individuals in our society continue to adhere to the old view that people with disabilities are not ca-

pable of living independently and productively in their communities, large segments of our society now believe that they have this capability. Moreover, perceptions of the competence and capability of people with disabilities are being reinforced by reality—the growing numbers of people with disabilities who are living in their communities successfully. Denying the ability of disabled people to live independently is difficult when interacting with them on the job and at the grocery, the theater, and the city hall.

Moreover, the majority of Americans now actually support the independent living goals of people with disabilities. This support was demonstrated politically through the enactment of the Americans with Disabilities Act of 1990 (ADA), a comprehensive civil rights law with the purpose of ensuring inclusion of people with disabilities in all aspects of our society. ADA, which represents the culmination of the first major stage of the independent living movement, also has provided a strong impetus for the expansion of the movement. The increased accessibility of our society resulting from compliance with and enforcement of ADA, in conjunction with access to new technologies (e.g., Internet, e-mail, voice recognition, reading machines, and communication devices), have enhanced the ability of people with disabilities to live independently. These factors have also facilitated the ability of disability rights leaders to mobilize this constituency politically.

There is now a consensus that the goal of disability policy is to ensure that people with disabilities are fully included in the mainstream of our society and have the opportunity to live independently in their communities. Disability rights advocates and researchers have argued that we must bring the goals and policies of other disability laws and programs, including the Social Security disability programs, in line with the independent living goals of ADA (National Council on Disability, 1986, 1988; DeJong & Batavia, 1990). This growing consensus both within the disability community and among

the public at large suggests that there will be growing political support for a program that allows people with significant disabilities to live independently. The public support is likely to be greatest if the program can be funded primarily from a reallocation of resources from existing disability programs that are not as consistent with the independent living model goal (i.e., public funding for nursing homes and home health agencies).

Recent Proposals for a National Personal Assistance Services Program

A variety of national legislative proposals for personal assistance services programs have been set forth over the past two decades (Batavia, DeJong, & McKnew, 1991). None of these have been enacted at this time. Most of the bills did not receive substantial political support, in part due to lack of understanding on the part of most legislators concerning personal assistance services under the independent living model and to the well-organized political opposition of the nursing home and home healthcare industries. A few of these proposals achieve their financing through reallocating resources from these industries that operate under the medical model to consumers under the independent living model. However, none of these proposals received significant public attention.

One proposal that was noticed, at least within the disability community, was the Clinton Administration's personal assistance policy within its massive healthcare reform proposal in the 103d Congress (Health Security Act, 1993). There were two major components of this personal assistance proposal. The first component involved a new federal program administered by the states, organized in some ways similar to the Medicaid program but without strict entitlements, to expand the provision of personal assistance services. This was directed primarily at the nonworking population of people with disabilities who were Medicaid recipi-

ents and the working poor. The second component entailed a tax credit for the cost of personal assistance services. This was directed primarily at the working disabled population and was intended to reduce the enormous financial burden that a working person who requires substantial personal assistance services must bear. In my opinion, this was a sound and fairly comprehensive proposal and one of the few intelligent aspects of the Clinton healthcare plan.

More recently, the Medicaid Community Attendant Services Act (H.R. 2020), commonly known as MiCASA, was introduced in the 105th Congress. The main objective of this legislation is to expand coverage of personal assistance services by allowing the allocated Medicaid funds to follow the individual to whichever setting he or she prefers to receive personal assistance services. Specifically, this bill allows Medicaid recipients who are eligible for nursing facility services or intermediate care facility services to choose, if they wish, to use these funds for "qualified community-based attendant services" in the "most integrated setting appropriate to the needs of the individual." This

bill, which significantly is sponsored by Speaker of the House Gingrich, currently has bipartisan support.

When the first bills for national personal assistance services programs were developed, very few politicians or their staff members understood what personal assistance services are and why they are so important to many people with disabilities. Many still do not understand these issues adequately. However, over time, there has been a learning process associated with the political process of developing, marketing, and considering these bills. Now, for the first time, there appears to be a critical core of Senators, Congressmen, and their staff people on Capitol Hill who are knowledgeable of personal assistance services, particularly at the committee level (e.g., the Senate Finance Committee). Each new bill increases the understanding of the Congress on this issue and increases the grassroots organization of the disability community for lobbying for this bill. Eventually, assuming that an acceptable financing mechanism can be found, the threshold may be passed for enacting a comprehensive national program.



Expansion of State Medicaid Waivers for Personal Assistance Services

Under substantial political pressure from disability rights groups, and not willing to wait for establishment of a national program, several states have used the waiver authority under the Medicaid program to establish their own statewide personal assistance services programs under variations of the independent living model (Doty, Kasper, & Litvak, 1996). These programs have served as a natural experiment on the financing and provision of personal assistance services. Analysis of their structures, functions, and outcomes has provided valuable information for purposes of establishing a national program (Kennedy & Litvak, 1991; Egley, 1994).

Enhanced Interest Among Older People in the Independent Living Model

As the baby boom generation approaches senior citizen status, interest in the independent living model of personal assistance services is likely to grow substantially. Even the current generation of older Americans indicates a growing strong desire to maintain control of their lives to the extent possible if they become disabled (Glickman, Brandt, & Caro, 1994; Doty, Kasper, & Litvak, 1996). However, this generation did not grow up with people with disabilities who live independently in their communities. They are, therefore, not very familiar with the independent living model and its potential to allow them to maintain autonomy in the event that they become disabled. Many of them are resigned to receiving long-term care services in a nursing facility, if such assistance becomes necessary, but they dread the day that they must leave their homes permanently.

In contrast, the aging baby boomers (and the generations that follow) are much more likely to have some familiarity with the independent living

model, or are much more likely to be advised of the existence of this model at the time they become disabled. Their peers with disabilities express a high level of satisfaction with this model (Beatty, et al., 1998.) and have experienced positive health outcomes under it (Nosek, 1993). Already, in response to market demands, long-term care policies are being established that provide a cash benefit that may be used for purchase of personal assistance services under the independent living model. Many baby boomers and members of younger generations who have witnessed firsthand their grandparents' and parents' loss of autonomy when receiving nursing home care or home health services under the medical model have determined that they want a different approach for their own long-term care.

This change in attitudes among the near retirement and younger populations, which is in part a consequence of the broader paradigm shift that is occurring, again suggests that a national personal assistance program is likely to become more viable in the coming years.

Relative Decrease in Power of the Nursing Home and Home Health Industries

Perhaps the strongest reason that the independent living model of personal assistance services has not grown as rapidly as feasible is that healthcare providers that benefit from the status quo have rigorously opposed it (Batavia, DeJong, & McKnew, 1991). Their primary argument has always been that people with disabilities will be harmed under the independent living model and that providers who are either professionally trained or supervised by healthcare professionals are necessary to ensure quality and avoid negligence or abuse. This argument has lost much of its strength in recent years as evidence has mounted concerning negligence, abuse, and rampant fraud in the nursing home and home health industries. Policymakers have realized that the appropriate comparison is not between

one model that is subject to problems and another model that provides perfect patient care, but rather between two models that are potentially subject to quality and abuse problems. The policy challenge is to provide services under the model preferred by the consumer in a manner that minimizes the likelihood of problems.

The problems identified in the nursing home and home health industries have compromised their public image, adversely affecting their political clout at both the federal and state levels. When providers dominated the healthcare system, prior to the 1980's, industry trade associations were highly effective in their lobbying efforts to eliminate potential competition. As the healthcare field has become more and more payer-dominated, and to some degree consumer-dominated, the lobbying effectiveness of provider groups has been diminished relative to other interests. This is particularly true concerning components of the industry that have been under attack for reasons concerning fraud and/or quality of care issues, such as nursing homes and home health agencies.

This is certainly not to suggest that these industries have lost their political power altogether. In fact, some nursing facilities and home health agencies have probably gained power through consolidating with large healthcare systems with significant resources for lobbying. However, as industries, overall they have lost power relative to competing political interests such as people with disabilities who have become more organized politically in the past decade, as evidenced by enactment of ADA. This relative increase in the political clout of people with disabilities as a potential voting block may accrue to the benefit of the independent living model and programs organized under it.

Two Key Policy Choices

A broad array of policy choices must be made in establishing a national personal assistance program. Many of these choices have been discussed previously and will not be reconsidered

here (Nosek, 1991; Batavia, DeJong, & McKnew, 1993; Kennedy, 1993). However, two major issues have not been considered extensively—whether benefits should be provided in-kind or in cash and whether services should be available under models other than the independent living model (such as the medical model).

Benefits In-Kind, in Cash or in Cash Equivalent.

Currently, most state programs provide services in-kind. This means that a determination is made by the program as to how many hours of services the consumer may receive under the program and the consumer receives those services. The consumer does not pay for the services directly; the program does so on behalf of the consumer. Some of these programs are structured to allow significant consumer direction and control. However, most do not, and few entail the amount of consumer choice built into this model that would exist in a program in which the consumer controls the funds (Nosek, 1991; Batavia, DeJong, & McKnew, 1993; Kennedy, 1993).

A few programs actually allow the consumer to control the funds. The most prominent of these programs is the Aides and Attendant Allowance program of the Department of Veterans Affairs, which provides cash benefits to disabled veterans based upon an assessment of their personal assistance requirements (Batavia, DeJong, & McKnew, 1993). This program applies only to eligible disabled veterans and is an exception to the general rule that services are provided in-kind. A few states and several nations have also been experimenting with cash payments for personal assistance services (Cameron & Firman, 1995).

However, the fact that the model of in-kind personal services dominates at the current time does not mean that these services must be or should be provided in-kind (Batavia, 1996). Presumably, if all other factors were equal, the individual with a disability would prefer a cash benefit to an in-kind ben-

efit of equal value. The cash benefit would offer far greater flexibility for the individual to pursue his or her independent living goals. However, for a variety of reasons, some people with disabilities currently prefer the benefits they receive in-kind rather than in cash, and many policymakers prefer to offer them in-kind.

From the perspective of the policymaker, who is accountable to the taxpayers financing these programs, a cash benefit does not provide the assurance that the money will be spent in a manner that would satisfy taxpayer concerns. This assurance is critical to ongoing political support for the program. For example, a cash benefit might be used by a beneficiary for better nutrition or housing. While this may be a rational decision on the part of the beneficiary, taxpayers who believe that they have paid for personal assistance services, not a higher standard of living generally, may resent this use of program funds. Some policymakers do not trust beneficiaries to make accountable decisions. In the worst case scenario, policymakers are concerned that some beneficiaries may use the cash for entirely unjustifiable purposes, such as the purchase of alcohol or illegal drugs. Such relatively rare cases, which are occasionally revealed through the press, can jeopardize support for an entire program.

From the perspective of beneficiaries, an equivalent cash benefit has two significant downsides. First, they are concerned that a cash benefit does not guarantee the ability to purchase the service previously obtained through the in-kind benefit. Second, they are concerned that, even with such reforms, there will be a political tendency for the cash benefit to be set below the level necessary to obtain adequate services.

The concept of using a cash benefit, in conjunction with counseling services available to the consumer, is currently being tested in a major research and demonstration project called the *Cash and Counseling Demonstration and Evaluation Project*, funded by the Robert Wood Johnson Foundation and the Office of the U.S. Assistant Secretary for

Planning and Evaluation at the Department of Health and Human Services (see article by Simon-Rusinowitz in this issue). The results of this project will provide significant insight into whether a program that uses cash payments directly to the consumer is economically and politically feasible (Simon-Rusinowitz, et al., 1998).

An alternative to the strict cash approach that may better satisfy the concerns of some policymakers is a model based on "cash equivalents." A system based on vouchers, Medical Savings Accounts (MSAs)¹ or tax credits that would provide a cash equivalent limited to the purchase of specified services will satisfy the accountability needs of many policymakers. With respect to a tax credit, making it "refundable" and therefore available to individuals with no tax liability could equitably provide support for all individuals who require services. Whether this cash equivalent approach is feasible will depend largely on whether it can be structured to satisfy the significant concerns of beneficiaries and policymakers. In specific, there would have to be some assurances that the voucher, MSA, or tax credit would be sufficient to obtain the needed service over the long term and that it would not be unduly subject to fraud and abuse.

What About Those Who Want Their Personal Assistance Services Under Another Model?

As indicated above, my colleagues and I recommended establishment of a national program based on the independent living model. This raises a key question. What should we do about requests by people with disabilities to receive their personal assistance services under a different model? Some purists within the independent living movement would not allow services to be provided under other models, and particularly the medical model, as options. My view is that this position is paternalistic and unacceptable. Who are we to determine which model should be available to other individuals with dis-

abilities? Even if we are entirely convinced that the independent living model is in the best interest of people with disabilities, we should not impose that judgment on the entire disability community.

For example, I have a friend with quadriplegia who decided that he prefers to live in a nursing home. Although I disagree with his conclusions as they apply to my own situation, his rationale is entirely sound and unrefutable. He contends that the nursing facility that he has chosen, which is a high-quality facility, offers him the security that he desires in living his life. Unlike someone who receives personal assistance services in their homes under the independent living model, he never needs to spend any time or money advertising for and interviewing personal assistants. He never has to fill out all the paperwork concerning taxes, unemployment insurance, and workers' compensation.

This raises another important point concerning the independent living model that rarely receives much attention. The model, at least in its pure form, imposes a large administrative burden on the individual with a disability. The government treats people with disabilities who employ personal assistants just like any other employer, including the filing of quarterly tax and unemployment insurance forms. These responsibilities can be extremely onerous, and are clearly a downside of the strict independent living model. A modified version of the independent living model could use independent living centers or other nonprofit entities to alleviate this burden for people with disabilities.

The independent living model is not for everyone. It is probably not for someone who has very limited capacities for self-direction (although a modified version of the model that uses surrogacy may be applicable to such individuals). It may not be for someone who has a limited desire for self-direction. It is also probably not for someone who is unable or unwilling to cope with risks, because there are definitely risks associated with bringing strangers into

one's home and with receiving care from a person who is not adequately familiar with disability-related problems. Under the independent living model, the individual with a disability is responsible for screening, training, and monitoring personal assistants; a mistake in any of these processes can be fatal. However, nursing homes and home health agencies are also far from perfect in screening, training, and monitoring their employees and, therefore, present similar risks.

The independent living model is for the majority of the disabled population who want to control their lives and are willing to bear the responsibilities and risks for doing so. These individuals should have consumer-directed personal assistance services available to them in their homes and communities. Therefore, in establishing a national personal assistance services program or policy, I would insist upon the independent living model being a primary option for people with disabilities. Beyond that, the government should adopt a neutral posture, neither favoring nor disfavoring any particular model. The person with the disability should be allowed to choose the model under which he or she receives services. All bias in favor of institutional providers, such as nursing homes and home health agencies, should be eliminated.

Conclusions

Access to personal assistance services often means the difference between

a free life in the community and a severely restricted life in an institutional setting. Even in the best institution, an individual with a major disability cannot choose exactly when to get out of bed, to bathe, to dress, to eat, to pursue his or her interests, and to return to bed. Individuals who require full-time personal assistance (e.g., attendant care) and who cannot obtain those services are not able to live in their communities. If people with disabilities who are recipients of Supplemental Security Income, Medicaid, and other government benefits will eventually lose their personal assistance as a result of accepting employment, it is not in their interest to accept a job that does not provide long-term assurance of at least comparable benefits, or their cash equivalent.

Many people with disabilities indicate that they would strongly prefer to receive their personal assistance services under the independent living model. However, the best way to determine the actual preferences of people with disabilities is through the choices that they make under a neutral program that allows them to choose among a broad array of long-term care/personal assistance options. The prospects for establishing a national program that offers such choice appears to have increased in recent years as a result of the five recent developments discussed in this article. Specifically, the political acceptability of a national program has grown with the


- increasing public acceptance of the goals of the independent living movement,
- increasing acceptance of the independent living model by older people with and without disabilities,
- specific proposals that have been advanced,
- insights obtained through Medicaid waiver programs for home and community-based personal assistance services, and
- decreasing clout of the healthcare interests opposed to the independent living model.

This does not mean that enactment of a personal assistance services program is inevitable. Nothing in the political

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arena is inevitable, and the establishment of any new national program—particularly at a time of conservative retrenchment from large national programs—is a longshot. Certainly, there is almost no chance of establishing a new open-ended entitlement program. However, the odds in favor of enacting a fiscally responsible program, with substantial controls against fraud and abuse, are now better than they have ever been. Whether such a program will be enacted will depend largely on whether the economy continues to expand and whether disability rights activists will be successful in getting their message through in a manner that is consistent with the goals of policymakers.

Opponents will argue that this is just another wasteful big government program. Politicians and other policymakers will have to be informed that we are not establishing a massive new program from nothing. Rather, we are replacing an array of poorly coordinated programs currently costing the taxpayers tens of billions of dollars that are not adequately meeting the needs of people with disabilities with a well-coordinated program that meets their needs based on their preferences. 

Note

1. An MSA is a tax-advantaged savings account, similar to an Individual Retirement Account (IRA), which could be used for certain specified purposes (e.g., medical costs, long-term care, personal assistance services) and could accumulate from year to year (Goodman and Musgrave, 1992).

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Personal Assistance Services Policy: Where We Have Been and Where We Are Going

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The Problem

Personal Assistance Services (PAS) policy at the national, state and local level has profound impact on individual consumers and on the ability of rehabilitation professionals to realize gains for their significantly disabled clients. Like many disability services in the United States today, PAS faces a peculiar dilemma. The new realities of the composition, demands, and ideology of the disability population are not well served by a delivery system which is no longer suited to those new realities. The PAS system has developed as the disability population has changed substantially. The population is aging, creating a large pool of people with disabilities who are older, though recent data show that the size of the disabled population that is over age 65 is and will continue to be smaller than anticipated (Manton, 1998). In addition, due to improvements in medical technology, people with much more significant disabilities—whether acquired at birth or as a result of work, recreation, or war injuries—are surviving longer. The independent living movement—the civil rights movement for people with disabilities—arrived in the 1970's, demanding control, individual choice, an end to dependency upon well-meaning but disempowering professionals, and a view of disability as stemming largely from barriers which have been created by society. This view culminated in passage of the Americans with Disabilities Act (ADA).

Yet, current PAS policy remains inconsistent with precepts of ADA. The promise of ADA for significantly dis-

abled people is hollow if they cannot get out of bed, get dressed, plan their day, and get out of the house in order to go to work or take advantage of increased public and government access.

Stages of System Development

The PAS system is a phenomenon of the last half of the 20th century. There have been three periods of system development. The first stage was the adaptation phase, when states modified old systems and programs to meet contemporary demands. The first PAS programs were jerry-rigged from systems built in the late 1950's and early 60's for other purposes. The earliest PAS programs developed from social welfare programs for protection against abuse, neglect, and the ravages of poverty, using chore workers who were sent to families to help them in time of need (Litvak, Heumann, & Zukas, 1987).

Over the past 30 years a gradually increasing number of states chose to make PAS an entitlement under their Medicaid program (Litvak & Kennedy, 1992). Medicaid provides health, hospitalization, and institutional care as well as a wide variety of optional health related services to "aged and disabled" people. However, there are still 18 states with no "personal care option" included in their Medicaid state plan. The provision of PAS in the community is left to state discretion, while every state is required to provide institutional and nursing home placement for people with disabilities under Medicaid (Harrington, et al., 1998). There are two serious results of this state discretion not to provide PAS in the home and community.

First, 20 percent of the people who need PAS, consume over 80 percent of the federal long-term service dollars be-

cause they live in nursing homes and institutions (GAO, 1994; Pepper Commission, 1990). The need for PAS is not new, but nursing homes and institutions are an old solution. Medicaid's institutional bias is inconsistent with much of the literature which shows that elderly and disabled people prefer not to go to nursing homes and institutions. In Pennsylvania, advocates have been successful under ADA in requiring the state to provide community-based services, if the recipient prefers, rather than institutional services, as a result of the Helen L. decision (1995). The *L.C. v. Olmstead* (1998) pursued by Georgia litigants in the 11th Circuit, resulted in a related decision. If such decisions were implemented on a national scale, it would change the PAS system profoundly. A major shift in Federal Government policy in this direction was signaled by the July 29, 1998, letter of Sally K. Richardson, Director of the Center for Medicaid and State Operations. The letter advised State Medicaid Directors that even though the above "... decisions are only binding in the affected circuits, the Attorney General has indicated that under the ADA States have an obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs." She goes on to state that "the most integrated settings standard applies to ... State Medicaid Programs."

The second significant result of state discretion over whether to provide PAS in the home and community under Medicaid is that Supplemental Security

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Income (SSI) recipients who want to go to work face a major obstacle to receiving PAS if the personal care option is not available under Medicaid in their state. Section 1619 of the Social Security Act allows people to receive Medicaid benefits after they have returned to work, including PAS (where available). (SSI is paid to people over 18 years old who have not worked enough years to be able to receive Social Security Disability payments.)

Medicare is another program which has been adapted somewhat to serve PAS needs. Medicare is health insurance for acute healthcare and primary care. Medicare pays for home healthcare for those needing medical care at home. Over the years, home health agencies have found ways under Medicare to provide PAS services to people with chronic conditions and disabilities, using home health aides. Due to the lack of 1619-like provisions for SSDI Medicare recipients, however, there is no provision for an individual to return to work and still receive some public assistance for home health services over an extended period of time. (SSDI is paid to workers who have become too disabled to work.)

The second stage, the gap filling phase in the development of PAS, began in the 1970's with the establishment of new programs geared to PAS for certain "targeted" populations. Beginning in the late 1970's, a few programs were developed using only state dollars for people who work and therefore earn too much to qualify for federally funded PAS programs. Often, these programs developed with heavy involvement of the state vocational rehabilitation agency (e.g., in Massachusetts, Illinois, and Ohio). Generally, program participants pay for their PAS on a sliding fee basis according to their income from which disability expenses have been excluded.

Title III of the Older American's Act targets older people who earn too much from Social Security and other sources to get PAS through Medicaid and state funded programs. It covers a very wide and varied number of services older people could use in order to remain in

the community. For the most part, the small amount of money allocated by Congress to implement Title III did not go toward PAS in most states, and there has been little increase in funding from Congress for years.

The next gap filler programs were the Medicaid waivers geared first to aged and disabled people, then gradually to people with developmental disabilities, people with traumatic brain injury, technology dependent children, people with high medical needs, and people with AIDS. The purpose of the waivers was to prevent or reverse institutionalization. In general, they provide a richer set of services compared to other PAS programs.

There are several problems with the waivers, however. They are temporary and states need to reapply for them on a regular basis. They are aimed at serving only those who have been or would be in institutions, so the pool of money available is only that which would have been available to cover recipient needs based on existing nursing home and institutional beds. The amount of money the states receive per consumer is different, depending upon the cost of institutional care for these varied populations. Consumers who would otherwise be living in acute settings receive the most money for services in the home, followed by those with developmental disabilities and, lastly, those with later onset physical disabilities. The waivers limit the number of people served and generally have long waiting lists. Many of the 18 states have not chosen to provide PAS in the home and community as an entitlement in their regular Medicaid program, but have built their PAS system on these relatively small waivers in order to avoid implementing an entitlement program; and, in all states the waivers have led to large sums of money being available to serve a relatively small number of people in programs that rely, generally, upon high priced agency providers.

Fueled by the Medicaid waivers, this second gap-filling stage has resulted in a huge increase in number of programs and somewhat of an increase in numbers served. A directory of the ex-

isting programs in every state will be available from the World Institute on Disability (1998). This directory is a way for consumers, rehabilitation professionals, researchers, and advocates to know more about the PAS system in their area and across the United States. The latest stage involves two trends: the consolidation and centralization of programs at the state level and the introduction of much more consumer control and participation in the management of their PAS. The consolidation is occurring in order to realize efficiencies of scale across age and disability by combining similar programs under one administrative body. State councils and task forces have been forming to analyze their PAS system as a whole (e.g., Wisconsin, Texas, New York, and Massachusetts). The State of Oregon took this process one step further and combined all long-term services for younger and older disabled people so that admission to a nursing home depends upon rejection of all possibilities for service in the home and community. Over the years, Oregon has repeatedly demonstrated how cost-effective this can be. Another consolidation trend being considered on the state level is to link PAS to managed healthcare in a further move to rationalize the PAS system. Arizona has taken this process the furthest to date. A key task of the World Institute on Disability's Rehabilitation Research and Training Center on Personal Assistance Services (RRTCPAS) is to monitor these and other policy changes in the PAS system.

The introduction of more opportunities for consumer control and direction is the other new trend in the system. Studies relating to this trend are well represented in these two special issues of *American Rehabilitation*. Interaction between the disability community and elderly community has resulted in fruitful exchanges on the issue of consumer control for older people (Kane, 1995; White House Conference on Aging, 1995). This interest is reflected in the publication of *Consumer Choice News* as a joint effort of the National Council on Aging and the World Institute on Disability. PAS for those with psychiatric disabilities is in its

infancy and is poorly understood by consumers and professionals alike. Several states have adapted the PAS model to support people with psychiatric disabilities with cuing to perform their daily routine, including taking medications. Some are thinking about more sophisticated options such as advanced directives so that the personal assistant will know the consumer's wishes regarding hospitalization and treatments when the consumer experiences an exacerbation of his/her condition (L. Stewart, 1996). We are seeing programs springing up to support people with cognitive disabilities, both with and without physical disabilities, to facilitate their living in homes of their own rather than group homes (Vivona, V., Eckels, K., Dresen, J., & Zukas, H., 1998). Sally Richardson (personal communication, Spring, 1998) stated in her letter to State Medicaid Directors that the "forthcoming State Medicaid Manual will define personal care services" in terms of need for assistance with ADL's and IADL's so that the states can go beyond physical tasks to include cognitive and safety assurance tasks. Yet the availability of a range of programs designed for all populations does not exist in many places. Every state is different and no state meets the needs/demands of all populations equally.

Achievements and Problems

The PAS system has achieved much to date. From a service available in only a handful of states it has evolved so that there are PAS services in every state. More and more new people are being served. Since the 1993 Health Care Reform Task Force, PAS is seen by policymakers as a cross-disability as well as a cross-age issue (Health Security Act, 1993). Consumer direction and control has become a viable option. Studies of consumer-directed services, cost of various models, legal analyses of liability, as well as demonstrations of consumer-driven models among people of all ages in several states and in Europe are showing that many consumers prefer PAS arrangements that allow them to be in control and that such programs are

legally and economically feasible (Egley, 1994; Sabatino & Litvak, 1996; Beatty, 1998; Benjamin, 1998; Reiff, 1996; Cameron & Firman, 1995).

Attention is being drawn even more to PAS as a work necessity. Due to the 1992 Rehabilitation Act Amendments, vocational counselors must include PAS in IWRP's so that clients and counselors begin to plan for PAS needs preclosure. Research is finally coming out that shows, as disabled people have long maintained, that there is an increase in work and community engagement when one has PAS (Richmond, Beatty, Tepper, & DeJong, 1997; Nosek, Fuhrer, & Potter, 1995; Kimmich, 1991.)

Publicly funded PAS programs that increase income and asset limits for eligibility and thereby encourage competitive employment are rare, small, and largely state-funded, but could stand as models (Roth, 1992). In theory, any program that offers the choice of hiring and managing independent PAS providers cannot monitor whether recipients use PAS at work. The key issue then becomes the income and asset limits that the program imposes to determine eligibility. As noted earlier, the passage of 1619 has allowed people on SSI to work and receive PAS in states where PAS is available to Medicaid recipients.

The recently launched Cash and Counseling demonstration projects supported by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services theoretically will allow people to customize their PAS and use their money to shape the personal assistance provider market. Money that follows the individual leads to personal and family empowerment, the ultimate consumer control model. Many problems remain, however, with the PAS system. The system is a patchwork quilt that has holes in it and doesn't quite cover all those it might. Two of the major problems which remain have received attention by Congress in the last period:

- penalties for work, marriage, and scholastic achievement and
- wide variation in proportion of PAS users served in public programs across the states.

The other major problems are:

- the absence of adequate training or "Counseling" for new PAS users, including those in transition from school to work,
- the absence of emergency backup services,
- the dearth of personal assistance providers,
- the lack of understanding of the nature of abuse experienced by PAS users and the successful methods that consumers use to counteract that abuse, and
- the lower participation rates of people of color in PAS programs.

The last four problems above have not been addressed yet by federal policymakers, but there are several state and local initiatives, demonstrations, and research projects aimed at finding ways to solve these problems.

Abolishing Work Penalties

On the state level, Medicaid waivers for working people are beginning to appear at state discretion as a result of the Balanced Budget Amendment of 1997. The Amendment attempted to fill the gap for PAS users who want to work by extending income eligibility limits for those on SSI and instituting a Medicaid waiver for working disabled people who are on Medicaid and/or on SSI. These waivers also may enable SSDI PAS users to return to work because eligibility is not linked to being an SSI recipient, but only to being SSI eligible. However, the waivers have severe limitations in that individuals still have to be low income to be eligible, unless the state chooses to raise the income eligibility limit. Also there is no incentive for states to institute such a buy-in and in many instances the amount of money needed to "buy" waiver services is prohibitive. State vocational rehabilitation agencies could play a key role in encouraging the development of these new PAS programs in their state and making them truly accessible.

The recently crafted Jeffords-Kennedy Bill (1998) is an attempt to ameliorate these problems by lifting the income and resource limits for eligibility to

RESOLUTION ON PERSONAL ASSISTANCE SERVICES

*Passed by Participants of the International Personal Assistance Services Symposium
Sponsored by the World Institute on Disability, Convened September 29 to October 1, 1991, Oakland, California*

RESOLUTION

WE, PEOPLE WITH DISABILITIES AND OUR ALLIES, have come together from across the United States and around the world from September 29–October 1, 1991, in Oakland, California, at the symposium entitled EMPOWERMENT STRATEGIES FOR THE DEVELOPMENT OF A PERSONAL ASSISTANCE SERVICES SYSTEM.

This conference has focused on personal assistance services as an essential factor in independent living, which itself encompasses the whole area of human activities, including but not limited to housing, transportation, community access, education, employment, economic security, family life and interpersonal relationships of choice, leisure, and political influence.

Recognizing our unique expertise derived from our experience, we are taking the initiative in the development of policies that directly affect all people with disabilities. People with disabilities are entitled to be enabled to achieve the highest possible level of personal functioning and independence through appropriate education, health care, social services and assistive technology, including, as necessary, the assistance of other people.

We firmly uphold our basic human and civil rights to full and equal participation in society as called for in the Americans with Disabilities Act and the United Nations Universal Decla-

ration of Human Rights. We consider independent living and the availability of support services to be critical to the exercise of our full human and civil rights, responsibilities and privileges.

To this end, we condemn forced segregation and institutionalization as direct violations of our human rights. Government policies and funding should not perpetuate the forced segregation, isolation, or institutionalization of people with disabilities of any age. The Americans with Disabilities Act was passed into law to promote the equalization of opportunity. The passage of comprehensive federal personal assistance legislation is essential to realizing the historic promise of the Act.

The recommendations of the United Nations World Programme of Action (s 115) specifically state that "Member states should encourage the provision of support services to enable disabled people to live as independently as possible in the community and in so doing should ensure that persons with a disability have the opportunity to develop and manage these services for themselves."

In support of the international movement of disabled people and in Disabled Peoples' International, which has a special commitment to setting up a network of initiatives for personal assistance services as part of the implementation of the equalization of opportunities, we call on governments and policy makers to assure greater and more equitable access to personal assistance services based on the principles below:

1. Personal assistance services are a human and civil right. These services shall serve people of all ages, from infancy throughout a person's lifetime, when the person's functional limitation(s) shall necessitate the services. This right is irrespective of disability, personal health, income, marital and family status, and without discrimination on the basis of race, national origin, cultural background, religion, gender, sexual preference, or geography.
2. All people with disabilities (and their self-designated or legal representatives if applicable) shall be informed about their rights and options related to personal assistance services in accessible formats and appropriate languages. All levels of personal assistance services should respect the privacy and confidentiality of the user.
3. Personal assistance users shall be able to choose from a variety of personal assistance services models which together offer the choice of various degrees of user control. User control, in our view, can be exercised by all people regardless of their ability to give legally informed consent or their need for support in decision making or communication.
4. Services shall enable the users to exercise their rights and to participate in every aspect of sociocultural life including, but not limited to home, school, work, cultural and spiritual activities, leisure, travel, and political life. These services shall enable disabled people, without penalty, if they so choose, to establish a personal, family and community life and fulfill all the responsibilities associated with those aspects of life.
5. No individual shall be forced into or kept in an institutionalized setting because of lack of resources, high costs, sub-standard or non-existent services or the refusal and/or denial of any or all services.
6. These services must be available for up to seven days a week for as many hours as needed during the 24 hour period of the day, on long-term, short-term and emergency bases. These services shall include, but are not limited to assistance with personal bodily functions; communicative, household, mobility, work, emotional, cognitive, personal, and financial affairs; community participation; parenting; leisure; and other related needs. The user's point of view must be paramount in the design and delivery of services. Users must be able to choose or refuse services.
7. Government funding shall be an individual entitlement independent of marital status and shall not be a disincentive to employment.
8. Government funding must include competitive wages (based on consumer cost experience within the private sector) and employment benefits for assistants and related administrative and management expenses.
9. Payments to the user shall not be treated as disposable, taxable income and shall not make the user ineligible for other statutory benefits or services.
10. Sufficient governmental funding shall be made available to ensure adequate support, outreach, recruitment, counseling, and training for the user and the assistant. Government efforts shall ensure that a pool of qualified, competent assistance shall be available for users to access through a variety of personal assistance services models, including, but not limited to, individual providers and full service agencies.
11. The user should be free to select and/or hire as personal assistants whomever s/he chooses, including family members.
12. Children needing personal assistance services shall be offered such services as part of their right to inclusive education as well. Such education and personal assistance services shall include age appropriate opportunities to learn to use and control personal assistance services effectively.
13. There shall be a uniform appeals procedure which is independent of funders, providers, and assessors that is effected in an expeditious manner and allows the applicant/user to receive advocacy services and legal counsel at the expense of the statutory authority.
14. In furtherance of all the above, users must be formally and decisively involved and represented at all levels of policy making through ongoing communication and outreach in planning, implementation, design, and development of personal assistance services.

allow SSDI and former SSI recipients with higher incomes to buy into a PAS Medicaid waiver and gives grants to states if they opt to institute a Medicaid buy-in for workers.

Increasing Outreach

In general, social welfare policy in the United States is designed so that not everyone eligible for a program will actually come forward to receive it, either because of stigma, difficulties in applying, or lack of knowledge of the program. PAS programs are no different. In particular, ethnic and racial minority communities are impacted by the lack of targeted outreach to these communities (Eckles et al., 1998). CASA (HR2020) has been introduced as a result of much work on the part of the advocacy group ADAPT to extend PAS coverage in the community to everyone who is nursing home eligible under Medicaid regardless of the state. In a sense, this makes the Medicaid waivers permanent in every state and redirects nursing home funding to PAS.

Increasing Consumer Training

Training of disabled people to manage their PAS is a major contribution to improving the quality of PAS, along with increasing provider pay and benefits. Some centers for independent living (ILC's) have taken on the task of training people with disabilities to recruit, hire, terminate, train, supervise, and pay their providers. Unfortunately, most of the ILC's do not do this training on a regular basis because they are not reimbursed for it. Excellent training manuals are available. A list of some of the better ones can be obtained from the World Institute on Disability (WID, 1996). Rehabilitation professionals might consider making such peer support programs available to clients who need training.

Increasing PAS Quality/Supply

This is a chronic problem which begs for some innovative problem solving and demonstrations. Of particular con-

cern is the need to expand the work force that is willing to be managed by PAS recipients or their representatives. The RRTC/PAS at the World Institute on Disability is beginning to explore this issue and plans to make recommendations for creative solutions. Studies to date have shown that often paid family providers are preferred by PAS program recipients because they are more reliable and dependable (Benjamin, 1998; Commonwealth Commission, 1991). There are projects around the country attempting to train people with disabilities and former welfare recipients to work as attendants.

Expanding Emergency Services

We are aware of only one place in the country—Berkeley, California—that has a citywide emergency service for people whose independent providers do not show up for work. Several counties in California that have PAS public authorities to recruit and refer attendants are trying to make emergency service available through the public authority. Planning for emergency backup by individual recipients is also part of the management training process.

Abuse Prevention

Researchers at Portland's Oregon Health Sciences Center and the World Institute on Disability are studying the nature of abuse experienced by PAS users, ways for professionals to detect it, and methods for consumers to use to confront it (Powers et al., 1997).

Racial and Ethnic Minorities


There have been many studies in the aging literature on service needs and personnel issues regarding provision of long-term services to diverse populations. WID recently completed a first step in this direction in its research on the issue. Eckles et al. (1997) found that their Asian American, Latino American and African American informants attributed the lack of PAS to culturally diverse populations to "several factors, including: a) inadequate outreach. . . ,

b) inadequate accommodation to cultural needs (such as language translation), c) economic and wage-related issues such as inadequate provider wages and concerns about employing undocumented workers, d)...underepresentation of staff persons from ethnic communities in PAS agencies, e) token leadership/visibility for a few individuals in the independent living services system, and f) little or no understanding of specific cultural values and concerns about disability..." within diverse communities.

Visioning the Future

There are many organizations working on PAS legislative and regulatory change nationally, including the National Council on Independent Living (NCIL), American Disabled for Attendant Programs Today (ADAPT), and the Consortium for Citizens with Disabilities (CCD). State initiatives are springing up around the country to address the pressing need for expansion and improvement in the PAS system. These task forces involve all the PAS stakeholders, including consumers, trade unionists, Medical, rehabilitation and social service providers, government officials, and consumer advocates. Rehabilitation professionals are playing and can play an important role in the effort to chip away at the work, schooling, and marriage penalties embedded in the PAS system and in the planning to expand service availability, consumer training, emergency services, and a good quality personal assistant work force.

In the long run, the goal of many in the disability community is to achieve a system that mirrors the Recommendations from the 1991 Symposium on PAS held in Oakland, California, which built on the views of PAS consumers worldwide (*see side bar*). This would be a cross-disability, cross-age system, which is individualized and has no penalties for working, schooling, or marriage and serves all those in need regardless of income on a sliding fee basis. We have already made progress toward these goals. If the momentum continues we will be able to see more and more sig-

nificantly disabled people able to have access to "equality of opportunity, full participation, independent living, and economic self-sufficiency" (the goals of ADA). The expansion and improvement of the PAS system will continue because it makes fiscal, quality, and humanitarian sense. 

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California's Public Authorities

An Emerging Model for Consumer-Directed Personal Assistance Services Comes of Age

Paul R. Kumar

Created in 1973, California's In-Home Supportive Services program (IHSS)—with approximately 200,000 consumers and 180,000 providers—is the largest personal assistance services program in the United States. IHSS delivers personal care, domestic, paramedical, and other services necessary for seniors and younger people with disabilities to live independently at home and to avoid institutionalization.

In its first 15 years, IHSS pioneered the delivery of personal assistance services through the individual provider (IP) mode which gives consumers the right and the responsibility to select, hire, train, supervise, and fire their own providers. While counties had the option to deliver IHSS services by using their own employees or by contracting with private agencies, the IP mode proved to be the least costly and the best liked by consumers.

By the late 1980's, over 80 percent of IHSS customers statewide were being served by individual providers. However, despite its comparative popularity, the IP mode had profound, perpetual problems stemming from serious, structural flaws. These failings, which gravely undermined the quality of services for consumers and the quality of work for providers, included, but were not limited to:

- the lack of a registry system to link consumers in need of ongoing, respite, or emergency services with prescreened providers seeking employment or expanded work hours;
- the lack of training opportunities and technical support, both for providers seeking to enhance their skills and for



consumers seeking assistance to instruct and to supervise their providers;

- the lack of sufficient, formalized consumer input in the governance of the IHSS program;

- the lack of an employer of record for purposes of collective bargaining with whom providers could negotiate over wages, benefits, and other terms and conditions of employment and to whom providers could address work-related grievances; and

- the compensation of providers at the minimum wage with no benefits, leaving these caregivers—mostly middle-aged women, disproportionately people of color, and recent immigrants, many of them members of consumers' families—in or near poverty, with no sick leave, no holiday pay, no vacation time, no health insurance, no pension, and annual turnover rates of 40 to 60 percent.

Over the past decade, to address the IP mode's deficiencies while building upon its commitment to consumer direction, consumers and providers

throughout California have banded together to develop, promote, and win funding for what has been hailed nationally as an "emerging model for consumer-directed personal assistance services"—the Public Authority.

The Emergence of the Public Authority Model

In the late 1980's, California consumers and providers were each intensifying their efforts to address the shortcomings of IHSS.

Consumer activists, seeking to enhance their direction of services, to increase the availability of hours, and to establish more dependable access to providers, were alarmed as private agencies aggressively courted counties to address IHSS problems by converting to the contract mode. Disability activists

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in particular had been extremely dissatisfied with agency-based IHSS services and feared that an expansion of the contract mode would result in less consumer control, fewer hours, and a diversion of scarce funds to profit and administrative overhead.

Independent providers, working with the Service Employees International Union, were organizing to win an employer of record for purposes of collective bargaining and commitments of funding for wage and benefit improvements. However, their initial efforts—by protest and by administrative, legal, and political action—to get either counties or the state to assume responsibility for their terms and conditions of employment met with stiff resistance.

In light of these challenges, the two stakeholder groups—who were always mindful of their interdependence but who had previously experienced tensions over threatened tradeoffs between hours of service and levels of compensation—joined forces to work toward a solution that would, in the words of a contemporary slogan, “Keep what works, fix what’s wrong, and fund it!”

Perhaps even more important than the groups’ agreement on programmatic

demands regarding consumer direction and provider compensation was their commitment to ensure that both consumers and workers had formal representation and a strong voice in the design and management of the service system.

In 1992 and 1993, after several years of organizing around the problems of the IHSS program and the deficiencies of the IP mode, consumers and providers won their first major victories toward establishing a new model and new standards for personal assistance services.

After long refusing to do so, California filed a Medicaid State Plan Amendment establishing the Personal Care Services Program (PCSP) under Medicaid’s personal care option, thus qualifying some 65 percent of IHSS services for federal financial participation and immediately drawing an additional \$200 million of federal revenue into the state.

The legislature took action authorizing counties to establish Public Authorities as independent public entities to administer the IHSS program and requiring that such Public Authorities:

- establish registry and referral systems to match providers who meet screening requirements with consumers in need;

- provide access to training for providers and consumers;

- be governed by a body consisting of at least 50 percent present or past IHSS consumers or be overseen by an advisory committee of similar composition in the event that the county board of supervisors served as the governing body; and

- serve as the employers of record of independent providers (IP’s) for purposes of collective bargaining while guaranteeing consumers the right to select, hire, direct, and fire their providers.

While requiring counties to bear the state share of any administrative costs incurred and any wage and benefit increases agreed to by Public Authorities—thus placing them at a fiscal disadvantage to agency contractors whose costs were fully shared by the state up to overall caps—California did provide registry startup funds for Alameda, Los Angeles, San Francisco, and San Mateo Counties and filed an additional Medicaid State Plan Amendment claiming federal financial participation for Public Authority PCSP hourly program costs up to 200 percent of the state minimum wage.

At this point, despite the fiscal obstacles to establishing fully functional Public Authorities—and the efforts of agency contractors to address the IHSS program’s woes by promoting a managed care model for personal assistance that would cut costs by curtailing consumer direction and reducing hours of service—the trend toward the Public Authority model was clear. While advocates fought in vain to capture the federal revenues generated by PCSP for IHSS program enhancements, they quickly began planning their next state policy initiatives and organizing support for Public Authorities in counties throughout California.

By the beginning of 1997, some 90 percent of IHSS consumers were receiving their services from IP’s; agency contractors’ share of services had decreased from a 1987 high of 16 percent to less than 4 percent; Public Authorities had been established in Alameda, San Francisco, and San Mateo counties; Santa Clara County had adopted a



Public Authority ordinance; and Public Authorities were under consideration in Contra Costa, Los Angeles, and Sacramento Counties. After nearly a decade of effort by consumers and providers, the Public Authority movement was on the verge of major breakthroughs.

1997–1998: The Public Authority Movement Comes of Age

Over the course of 1997, the Public Authority movement achieved its first major improvements in IP wages and benefits and won state and county legislative gains that set the stage for seeking California's full commitment to the Public Authority model:

- San Francisco County, using its own funds to generate federal financial participation, committed to raise hourly pay to \$6.40—65 cents above the new state minimum wage—by early 1998 and to establish a health insurance plan for IP's;

- legislation passed which required full state participation in Public Authority administrative costs and set a precedent for considering state participation in the costs of Public Authority wage and benefit increases; and

- Los Angeles County, whose almost 90,000 consumers and over 80,000 providers make up some 45 percent of the IHSS program statewide, passed an ordinance calling for the establishment of a Personal Assistance Services Council (PASC) in conformity with the Public Authority statute.

In 1998, having recently won an additional Public Authority ordinance in Contra Costa County, consumers and advocates moved aggressively to consolidate and expand these breakthroughs and to win legislative and organizing victories that would decisively establish the Public Authority model as California's preferred mode of delivery for personal assistance services. During the 1998 state legislative session, Public Authority supporters and their allies fought to:

- win adoption of the California Legislative Analyst's Office recommendation—proposed in previous years by

legislators but rejected by the executive branch—to qualify share-of-cost and other "income eligible" IHSS clients for participation in the PCSP, generating millions of dollars in savings for the state and for counties, all or part of which could be dedicated to IHSS program enhancements;

- obtain enhanced state reimbursement of county costs for those counties which dedicate their "income eligible" savings to provider wage and benefit increases; and

- establish full state sharing of Public Authority costs for wage and benefit increases up to the hourly program cost cap of 200 percent of the state minimum wage, thus establishing fiscal parity between Public Authorities and agency contractors.

These goals, while audacious, were within reach. All three pillars of the campaign had State Assembly and State Senate leadership endorsements, broad rank-and-file legislator support, and the backing of numerous senior, disability, and worker advocacy organizations. However, Governor Pete Wilson firmly rejected these initiatives, with the exception of the plan to qualify "income eligibles" for federal financial participation. He first blocked inclusion of the other items in the budget settlement, then vetoed the trailer bill which embodied them, despite its passage with nearly two-thirds support by both the House and the Senate. These measures will be reintroduced in 1999 and new Governor Gray Davis has signaled his support in principle.

The Next Frontier: The Los Angeles County PASC

The next frontier for winning significant IHSS standards improvements is the very site that holds the greatest challenges and opportunities for developing the Public Authority as a model for the reconfiguration and enhancement of personal assistance services throughout California and the nation: the Los Angeles County PASC.

Over the summer and fall of 1998, consumers and providers worked to establish the governing board and de-

velop the administrative structure of the PASC and organize the required 10 percent show of interest to trigger a union representation election for LA County's approximately 82,000 IP's. This election will take place in January 1999 and over the following few months the parties will work to negotiate an initial collective bargaining agreement. In this work, advocates and administrators will begin addressing challenges and opportunities that can be grouped into three categories:

- The mammoth scale of the PASC—

After nearly a decade of effort by consumers and providers, the Public Authority movement was on the verge of major breakthroughs.

currently encompassing over 90,000 consumers and 80,000 providers and growing at a rate of over 3 percent per year—will require the development of substantial infrastructure to implement the registry and referral services, the training opportunities, and the enhanced service coordination envisioned by its proponents. The PASC's scale will also require that such infrastructure be designed and built systematically in a manner that can be replicated elsewhere, in whole or in part.

- The enormous diversity of PASC consumers—spanning the full range of ages, chronic and disabling conditions, cultural and linguistic communities, personal lifestyles, and relationships with their caregivers—and the similarly impressive diversity of PASC providers will require that service enhancements be established in a manner that is accessible and responsive to all of the program's participants. The development of the general systems and the specific accommodations necessary

to ensure that all PASC consumers and providers benefit from program improvements will provide an important case study and template for addressing questions of equity and accessibility in the design of consumer-directed personal assistance services nationwide.

* The chronic fiscal crunch in Los Angeles County—which led the county to prohibit the PASC from unilaterally imposing any new costs upon it—will require that the PASC seek additional sources of federal financial assistance in order to take major first steps toward establishing more responsive services for consumers and living wages and benefits for providers. At a time when Congress and the Administration are both exploring options for the expansion and enhancement of personal assistance services, the PASC provides an important test case for determining which new forms of federal financial assistance would be most effective in promoting program improvements and what mitigating medium and long-run cost sav-

ings could be generated by improving the availability and the quality of home and community-based services.

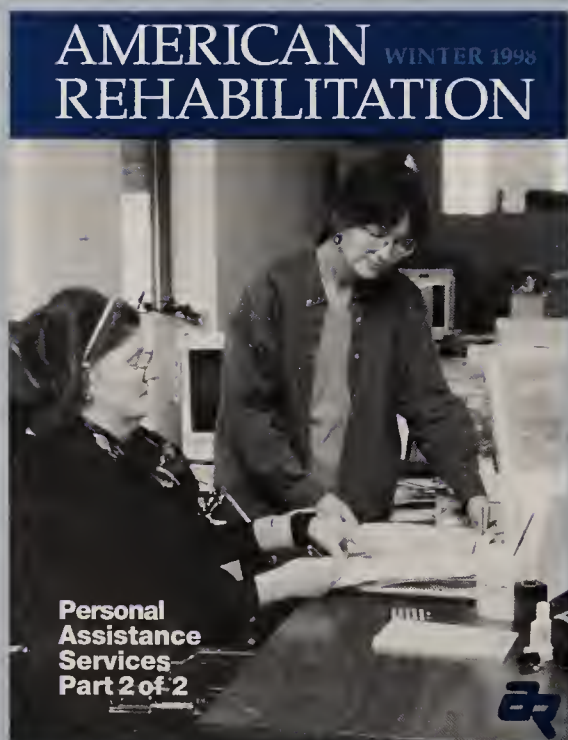
Conclusion

In a unique coalition effort, California consumers and providers of personal assistance services have banded together to develop a new model—the Public Authority—that will advance the aims of these key stakeholders on service and compensation issues while addressing the liability concerns and mitigating the cost impact of program enhancements upon the state and county governments. This unprecedented alliance required not only that each stakeholder group support the other's programmatic claims, but that both demanded formal standing and an organized voice in the service system.

However, while the Public Authority model shows great promise as an example of consumer and provider coalition work and as a template for the

improvement of personal assistance services, in order to achieve its promise it will require the direct attention and sponsorship of federal partners. The advances in consumer direction and governance, provider compensation and training, and service improvement and integration made possible by Public Authorities will only come to fruition with the additional federal commitment to and investment in quality home and community-based services that has been long overdue. Public Authorities are vital vehicles for change but they provide no substitute for focused federal action.

If, for the time being, the promise of Public Authorities swells the growing chorus of voices calling for increased federal support for home and community-based services and strengthens federal attention to consumer direction, quality of work, and organized representation of stakeholders in the service system as measures of progress and success, it will have done much good. **AR**



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The Home and Community-Based Services Work Group

partners with states, consumers, and others to advance the PAS agenda

The U.S. Department of Health and Human Services (HHS) is taking a leadership role in empowering people with disabilities—children, working age adults, and older people who need help with basic daily activities—and their families, by increasing their independence and quality of life. Under the direct guidance of the White House, HHS Secretary Donna Shalala has established a Home and Community-Based Services (HCBS) Work Group with the major goal of providing more opportunities for individuals to choose to decrease their reliance on nursing homes by increasing the available array of home and community-based services. The HCBS Work Group and other HHS activities to promote and expand home and community-based services and decrease unnecessary nursing home use are described in this article.

Ruth Katz

Approximately 11.6 million Americans who live in the community need assistance with routine activities of daily living, such as eating, going to the bathroom, getting in and out of bed or a chair, bathing, or getting around. (National Health Interview Survey, Disability Supplement, 1994.) Within this group are approximately 400,000 children, 5.3 million working age adults, and 5.9 million people over age 65. The range of disabilities experienced by these individuals includes mental retardation and other developmental disabilities, mental illness, cognitive impairment, musculoskeletal impairments, and others.

For many, long-term care is hands-on assistance with activities of daily living and associated tasks. For others, particularly those with cognitive impairments, long-term care takes the form of cuing or supervision. Most people get the help they need from family members or friends; estimates are that over three-fourths of long-term care is provided by such "informal care givers." However, many informal care givers could provide more services, and for a longer time, if they had some formal supports such as respite care or a limited number of hours of help per week.

For those who use formal long-term care supports, the federal/state Medicaid program is the primary public payer, covering 31 percent of long-term care expenditures. Only 1 percent is paid for by long-term care insurance. Approximately 39 percent of long-term care dollars are spent out of pocket by consumers each year. The remainder is covered by Medicare, VA insurance, and other sources.

Initially, Medicaid covered long-term care only in institutional settings, such as nursing homes and intermediate care facilities for persons with mental retardation. The only long-term care service that Title XIX (Medicaid) of the Social Security Act mandates be in place in each state is nursing facilities. However, in attempts to provide more cost effective services and in response to clear indications that consumers prefer to receive services in integrated settings—at home, and in the community—the Medicaid law has been modified over the past few decades to allow a range of home and community-based services to be covered by state Medicaid programs. Key among these services are those covered under the section 1915 (c) home and community-based waiver program.

Medicaid is a partnership between the states and the Federal Government. The Congress and HHS set the broad parameters, but states have a lot of flexibility in terms of which services to cover, how much to offer, the number of people covered, and expenditures. More people receive Medicaid long-term care services in the community, but the lion's share of spending is on expensive, institutional services. In 1997, total federal and state spending for nursing home services was \$32.5 billion; in the same year, spending for intermediate care facilities for people with mental retardation (ICF/MR) was \$9.9 billion. Comparatively, Medicaid non-

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institutional long-term care spending that year was \$13.5 billion (Burwell, Medstat analysis of HCFA 64 reports, April 1998). Most of the debate about long-term care focuses on some basic concerns about Medicaid, including an "institutional bias" in state long-term care spending, over reliance on medical models of care, and state long-term care inequities. The Administration's response to the challenges presented by this debate are discussed in detail in this article.

Activities Leading to Establishing the Work Group

Throughout the 1990's, HHS has taken several actions to make good on the Administration's commitment to expanding and promoting consumer-directed home and community-based services to enable people with disabilities to live the best lives possible. This position and these efforts are consistent with the Administration's views about the basic rights of all Americans to direct their own lives. It also is a natural extension of the Administration's rigorous support for equal rights for people with disabilities, as articulated in the Americans with Disabilities Act.

Secretary Shalala's Statement of Principles

In May 1995, after a series of meetings with individuals from the disability community, HHS Secretary Donna Shalala issued a set of principles supporting home and community-based care, reaffirming her support for home and community-based care and personal assistance services and offering consumers the maximum amount of choice, control and flexibility. Since then, HHS has significantly increased technical assistance to states to achieve these ends.

President Clinton's Meeting with Disability Community

In September 1997, President Clinton and Vice President Gore met with disability community representatives

to discuss how to move forward on a long-term care agenda. The President has a strong interest in the challenges facing people with disabilities who need long-term care services. He expressed continuing commitment to increase the availability of home and community-based personal assistance services (PAS). He also said he appreciated that the Medicaid Community Attendant Services Act (MiCASA-H.R.2020) bill had been introduced to help focus attention on the issue. MiCASA is an important vehicle for fostering discussion about how to move more toward a system where "the money can follow the person," no matter what setting the person chooses to receive services. Finally, he noted that a lot of the activity and decision making regarding home and community-based care and personal assistance services is happening in the states and said that states should help each other move forward.

The HCBS Work Group is Established

As a result of the meeting, and in an ongoing effort to pull together activities in this area, two HHS officials—Bob Williams, Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy, and Sally Richardson, Director of the Center for Medicaid and State Operations in the Health Care Financing Administration—took on the task of establishing and co-chairing a Work Group on Home and Community-Based Services. The goals of the group are to:

- address the "institutional bias" in spending for Medicaid long-term care services and reduce reliance on medical models of care;
- enable consumers and their families to choose the setting in which long-term care services are received, with increased flexibility for the "money to follow the person," as opposed to the financing determining the setting in which a person receives supports; and
- promote consumer direction of home and community-based personal assistance services.

Related Development

During the initial phases of the HCBS Work Group's activities, the President signed an Executive Order on the Employment of People with Disabilities. People with disabilities report that the fear of losing essential health and long-term care services covered under Medicare and Medicaid is an important factor in preventing them from leaving the federal income support programs—Supplemental Security Income (SSI) and Social Security Disability Income (SSDI)—and trying to work. Offering incentives that provide the necessary long-term care and personal assistance services could have a significant impact on helping these people enter the work force.

Not all people who need and use PAS will work; however, the concerns of SSDI and SSI beneficiaries who need PAS and want to work overlap with the focus of the HCBS Work Group. With secure, affordable availability of PAS, experts believe that many individuals with disabilities will be able to go to work. Thus, the HCBS Work Group has added to its areas of interest the question of work incentives for those on the SSI and SSDI rolls, to address their PAS and long-term care needs.

How is the Work Group Organized?

HCBS Work Group members include HHS and other Administration officials. Agencies represented include the Departments of Education, Labor, Housing and Urban Development, Transportation, and others. To ensure that the group's efforts are responsive to consumers, providers, and state officials, Deputy Assistant Secretary Williams and Director Richardson also established an expanded network of "constituency partners" with whom group members consult, in order to take multiple perspectives into account. The partners have been particularly helpful in guiding group members to model practices in the field; they have also served as a "reality check," commenting on how various proposals

might play out in the states and for individuals.

HCBS Work Group activities are predominantly accomplished through subgroups, each focused on specific goals. Three of the subgroups have been especially active in addressing the goals of the work group: the Demonstration Subgroup, the Model Practices Subgroup, and the PAS Workers Subgroup.

Activities of the Work Group and the Subgroups

The HCBS Work Group has undertaken the following tasks:

- *Identifying sources of Medicaid policies which promote an institutional bias, overmedicalization of certain services and inhibit consumer direction of services through the analysis of Medicaid (and applicable Medicare) provisions in statute, regulations, transmittals, and other documents and proposing remedies to address these issues.* HCFA contracted with the University of California, San Francisco, (UCSF) to conduct this independent analysis. The UCSF team, led by Charlene Harrington, Ph.D., reviewed federal Medicaid statute and regulations, as well as HCFA guidance on interpreting the rules, and came up with over 70 policy options to promote greater use of home and community-based services and consumer-directed models. The options range from providing technical assistance to states to regulatory and statutory reforms. In some cases, the proposed reforms are already allowable under current law, but not well known in the field. An independent Blue Ribbon Panel on PAS, led by Lex Friedan, served as the Advisory Group for the UCSF report.

- *Analyzing current proposals for home and community-based services reform (e.g., the CASA bill, the Feingold bill) and options for improving the cost effectiveness and programmatic feasibility of reform proposals.*

- *Examining options for linking the need for increasing the supply of qualified attendants with the work requirements of state welfare reform programs.* A report that reviews past

research and demonstration activities designed to train welfare recipients to serve as personal assistance workers has been completed. The HCBS Work Group will be discussing "next steps" to promote additional activities to train and employ new PAS workers.

- *Identifying demonstration and research options to test alternative strategies for restructuring the financing of home and community services to meet the goals stated above.* The group is exploring demonstration strategies, including opportunities that can be offered to states to modify their Medicaid programs and try some new ways of helping people who want to and are able to live in the community. It is anticipated that states will be given the opportunity to submit proposals to develop programs to identify individuals who want to and can successfully move out of nursing homes into the community and to build the infra-

In addition to waivers that offer personal care and other services, there are currently 31 states providing personal care services under their state plans.

structure to serve them in the community. This activity is in response to the Congressional directive in the Appropriations Bill.

In addition, HCBS Work Group members have recognized that in order to address concerns about unnecessary or inappropriate institutionalization, more knowledge is needed about the demographics and characteristics of people who live in nursing homes. The Minimum Data Set (MDS), a rich source of data on people in nursing homes, offers a unique opportunity to gain insight into certain nursing home residents. The HCBS Work Group is sup-

porting an analysis of the numbers and characteristics of nursing home residents who may be good candidates for moving back to the community and what they would need in the way of supports. Using this information, HCBS Work Group leaders anticipate being better able to help the states design strategies that succeed.

- *Identifying best practices in consumer direction of PAS in the states and establish a strategy to disseminate this information.* Members of the HCBS Work Group are developing strategies to address the President's charge that states should learn from each other how to support and promote home and community-based services. Some states are much further along than others; constituency partners, state officials, and others have provided much positive feedback about the value of a "state-to-state" technical assistance strategy. The HCBS Work Group is undertaking some technical assistance activities.

Model Practices Subgroup members have interviewed a range of experts, as well as representatives of numerous states, to learn about innovative approaches in locating individuals in nursing homes and assisting them to move to community-based settings and establishing and operating dynamic home and community-based service systems, particularly for individuals who need the level of care provided in nursing homes.

In discussions with constituency partners, state officials, and others, HCBS Work Group members learned that some states and some consumers are not fully aware of the flexibility available to them today. The members take seriously the need to clarify some of the things that states can do right now to reduce reliance on unnecessary nursing home care. HHS has contracted for a primer that explains to state officials and consumers what is possible under the personal care option, home and community-based waivers, and other Medicaid services and gives examples of states that have tried different strategies.

Related Activities to Expand Choice for Consumers Flexibility for States

The HCBS Work Group is active on many fronts exploring ways to push the agenda steadily forward toward the goals of expanding choice, promoting community services, and decreasing unnecessary reliance on nursing homes. However, even before the HCBS Work Group was established, a number of activities were underway (or completed) to address similar ends. The forum of the work group unifies the full force of all these activities and initiatives, combining efforts into a comprehensive, strategic approach. Following is a description of recent legislative, regulatory, policy, and research initiatives that HHS has generated to increase the availability of home and community-based and PAS services.

Legislation to Ensure That Certain Workers with Disabilities Keep Their Health Coverage

In the Balanced Budget Act (BBA) of 1997, Congress included an Administration proposal to allow certain workers with disabilities to purchase Medicaid. Losing health coverage can devastate anyone. Losing healthcare and personal assistance services is even more devastating for some people with disabilities—to the point where they are afraid to even try to work, because if they lose SSI or SSDI eligibility and, thus, healthcare, they lose their lifeline. The new BBA provision should enable many individuals with disabilities to go to work and become self-sufficient.

Soon after the enactment of this proposal, the Health Care Financing Administration mailed state Medicaid directors guidance on this new provision. That was followed by a letter that made the eligibility standard for the provision much more generous. It is anticipated that in states adopting this optional Medicaid service, personal independence, and productivity will increase for participants and a whole new group of taxpayers will be cre-

ated. This step forward is truly a win-win for all the American people.

Regulatory and Policy Advances

The Clinton Administration has been very supportive of expansions in home and community-based services. With 226 approved home and community-based waivers (authorized under Section 1915 (c) of the Social Security Act), all states are now operating at least one and sometimes several such programs, which offer an array of services to people who would otherwise be eligible for institutional or nursing home services. Thirty-nine states offer personal care as a waiver service and 13 offer attendant care. All services are offered at home or in other community-based settings. Under President Clinton's leadership, the waiver program has and will continue to flourish.

HHS continues to provide extensive technical assistance and guidance to states, enabling them to realize the largest increase in home and community-based waiver spending ever. State support and interest in the waiver program is at an all time high; between 1996 and 1997, total U.S. waiver spending increased by over 44 percent, while nursing home spending was up only 4.8 percent. (Burwell, MedStat tabulations of HCFA 64 data, April 1998.)

HHS has also taken a number of administrative steps to promote the use of waivers and to encourage consumer-directed services. For instance, last summer, Sally Richardson wrote a letter to state waiver officials in support of these ideas. In addition, a few years ago, HCFA sat down with state Medicaid officials and revised the state waiver application process, significantly streamlining it and, most importantly, removing the complex formula that required states to close a nursing home bed for each person served under the waiver. Today, because this "cold bed" rule is gone, states are able to simply specify the number of eligible individuals they plan to serve.

HHS also recently issued revised regulations to increase the responsiveness of the Medicaid personal care op-

tion to better meet the needs of people with disabilities. In addition to waivers that offer personal care and other services, there are currently 31 states providing personal care services under their state plans. Some states provide personal care under both a waiver and a state plan option. Under the new rules for the personal care state option, individuals are now permitted to receive services both in and outside of the home and the requirement that registered nurses supervise personal care services has been removed, thus reducing cost and making the service more consumer responsive and less "medicalized."

On a related note, HHS has undertaken some activities as a result of the Consumer Bill of Rights and Responsibilities issued by the Advisory Commission on Consumer Protection and Quality in the Health Care Industry. While the Medicare and Medicaid programs are largely in compliance with the Bill of Rights, there are a few administrative actions that the President has directed us to take to achieve full compliance. Of particular relevance to people with disabilities, HHS plans to include in regulations a provision that will ensure that individuals with complex and serious medical needs have appropriate access to specialists.

Research to Advance Knowledge and the State of the Art in Home and Community-Based Care

Research is also a key part of the HHS home and community-based care agenda to help policymakers, states, and consumers. It is critical to find out what works, for whom, how well, and at what cost. The department worked closely with the Robert Wood Johnson Foundation to develop an experiment to permit four states to offer consumers cash allowances along with counseling to purchase their own attendant services. The four states have requested permission to do this under the Social Security Act's Section 1115 demonstration waiver authority. These "Cash and Counseling" waivers are currently

under review. Once the program is underway, a comprehensive evaluation will examine the impact of this experiment on costs, quality, and consumer satisfaction. (Note: An article on the Cash and Counseling demonstration also appeared in the previous issue of *American Rehabilitation*, Personal Assistance Services, Part 1).

The Administration is also finalizing plans to work with independent living centers to start testing in four sites a model to help consumers purchase "durable medical equipment," such as wheelchairs. The aim of the "DME demonstration" is to improve the efficiency of purchasing and use savings to buy enhanced equipment not covered under Medicare.

HHS further promotes its home and community-based services agenda by working with individual states to develop and implement additional Medicaid demonstrations under the 1115 authority of the Social Security Act. Some focus on the integration of acute and long-term care, such as the projects underway in Minnesota and the District of Columbia. Others, such as the Colorado home health demonstration address long-term supports in a more targeted fashion. The Colorado 1115 program will develop and refine the independent care model in Medicaid home health services and assist individuals who are capable of doing so to direct their own services.

HHS leaders are very interested in helping states use the 1115 waiver authority to find new ways of doing business in Medicaid and encourage states to suggest ideas and proposals. These activities feed into and play off the efforts of the HCBS Work Group.


In addition to the 1115 demonstration waiver work, HHS has developed and carried out a solid research agenda on various aspects of personal assistance services. For example, in 1991, the department supported the World Institute on Disability to conduct a comprehensive *Survey of Medicaid Personal Care Programs*. The study offered a statistical profile of all Medicaid personal care programs, with indepth descriptions of six states' programs.

Under contract to HHS, researchers at the University of California at Los Angeles recently completed a study of the California In-Home Supportive Services (IHSS) program, comparing client-directed and professionally managed approaches to providing PAS. Another related project is addressing issues arising from regulatory compliance requirements. Among the elements of this study are: case studies of close to 20 programs that use a variety of intermediaries to determine how they assist consumers; and the development of model contracts reflecting current federal regulatory and other requirements.

Conclusion

The leaders and members of the Home and Community-Based Services Work Group are dedicated to continuing to stimulate more of the kinds of conversations needed at both the federal and state levels. Discussions and activities must focus on how to best provide consumers and their families with more opportunities to choose the settings in

which they receive long-term care services. The key is finding the most powerful incentives possible to support states to move in the direction of reducing reliance on institutional care and, at the same time, expanding and promoting consumer-directed home and community-based services. It is critically important for the Federal Government and the states to continue to work together to develop models and a broader array of consumer-directed and community services.

The Administration has demonstrated its support for this work group through ongoing activities and by establishing the HCBS Work Group. The challenge, of course, is to balance the goal of providing more flexibility and choice for people with disabilities with the need to ensure that the responses are cost effective and consumer responsive but also take advantage of and promote flexibility in current programs and innovation in states to help people obtain and keep the help they need to lead the best quality, most independent lives possible. 

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Determining Consumers' Preferences for a Cash Option:

New York Telephone Survey Findings

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Introduction

As long-term care expenditures have risen, policymakers have sought new ways to control costs while maintaining or increasing consumer satisfaction. Concurrently, there is increasing interest among the aging and disability communities in consumer-directed care (Kapp, 1996; Simon-Rusinowitz & Hofland, 1993; Ansello & Eustis, 1992; Mahoney, Estes, & Heumann, 1986), which is exemplified in the language of the 1994 Health Security Act (H.R. 3600, Kapp, 1996). One consumer-directed model, "cash and counseling," offers a cash allowance and information services to persons with disabilities—enabling them to purchase the services, assistive devices, or home modifications that best meet their needs. In principle, cash allowances maximize consumer choice and promote efficiency as consumers who shop for the most cost-effective providers may be able to purchase additional and more personalized services (Kapp, 1996). To determine if this is so, the cash and counseling model will be evaluated via a four-state demonstration project—the Cash and Counseling Demonstration and Evaluation (CCDE). The CCDE is co-sponsored by The Robert Wood Johnson Foundation (RWJF) and the U.S. Department of Health and Human Services, Office of the Assistant Secre-

tary for Planning and Evaluation (DHHS/ASPE).

The purpose of this article is to present findings from a telephone survey conducted in New York, the largest of the demonstration states, to assess consumers' *preliminary* interest in the cash option when compared to traditional services. The telephone survey was undertaken to discover how many clients might be interested in the cash option and to identify their demographic, background, and attitudinal characteristics for social marketing and communication purposes. The results of this survey were also used to guide the design of supportive counseling services and to ascertain what information consumers needed to make an informed decision regarding the cash and counseling option. So survey findings can be interpreted in context, we will first provide a little background information on the CCDE as well as information about existing personal care programs. Finally, key policy issues will be discussed.

Existing Personal Assistance Service Programs¹

Personal assistance services (PAS) encompass a range of human and technological assistance provided to persons with disabilities who need help with activities of daily living (ADL's), including bathing, dressing, toileting, transferring and eating, and/or instrumental activities of daily living (IADL's), such as housekeeping, cooking, shopping, and laundry. Public or private third-party payers can use any of three PAS financing methods: cash benefits (payments to qualified clients or their representative payees); vendor payments (a case manager determines

the types/amounts of covered services and arranges for and pays authorized PAS providers to deliver these services); and vouchers (clients use funds for authorized purchases). The CCDE will evaluate the impact of cash benefits.

In the United States, most existing public programs that finance PAS—including such major funders as Medicaid's optional personal care services benefit and home and community-based long-term care (HCBS) waiver programs—follow a vendor payment model. That is, the program purchases services for consumers from authorized vendors (i.e., service providers or equipment suppliers). In some programs, the list of covered services and authorized vendors is quite restricted. Other programs may have a broader range of covered services, adding adult day care, transportation, home modifications, and assistive devices. Clients may sometimes hire workers themselves (i.e., workers not employed by home health agencies) to be their in-home aide.

Until recently, the prohibition on direct payments to Medicaid clients has rarely been questioned. However, many state program officials have come to share the concerns of disability rights advocates who want PAS programs that promote consumer choice and avoid program rules that may foster dependency in the name of consumer protection and/or public accountability (Litvak, Zukas, & Heumann, 1987; Litvak et. al., 1990; Litvak et. al, 1991). In addition, state officials have a strong interest in achieving program economies. Most Medicaid PAS programs mandate that case managers (registered nurses and/or social workers) assess clients, develop and monitor care plans, and

authorize provider payments. Case management can be expensive, and researchers and administrators question whether it should be uniformly required (Jackson, 1994; Geron & Chasler, 1994). Hence, reasons for the growing interest in a cash option are savings on program administration and enhanced consumer empowerment.

Cash allowance programs are currently very small because they involve "state-only" funds. Up until this demonstration, states could not use Medicaid to fund cash allowances that permit clients to purchase their own services because of federal restrictions on direct payments to clients. Consequently, it hasn't been possible to evaluate large programs with a cash option. This policy-driven demonstration and rigorous evaluation will provide information about the costs, benefits, and implementation issues involved in a cash option so state and federal policymakers can make informed decisions about whether and how to implement this long-term care model.

Demonstration and Evaluation Design

As the national program office for this large project, the University of Maryland Center on Aging (UMCA) directs and coordinates the demonstration, oversees the evaluation, and provides technical assistance to the demonstration states. The national program office works in conjunction with the project Management Team comprised of project officers from the Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation, the evaluation team leader from Mathematica Policy Research, Inc., and advisors from the National Council on the Aging, the Health Care Financing Administration (HCFA), and the Social Security Administration.

In the winter of 1996/97, Arkansas, Florida, New Jersey, and New York each received grants of up to \$500,000 from RWJF to implement programs offering Medicaid PAS consumers the choice of a cash benefit instead of

agency-delivered care. Some major program characteristics are:

- States will include both elders and younger adults with disabilities. Florida will also include children with developmental disabilities.

- Arkansas, New Jersey, and New York are offering a cash alternative to their Medicaid Personal Care Option, while Florida will include its Medicaid Home and Community-Based Care waivers.

- Funds must be used for personal assistance services: i.e., personal care workers and home renovations and/or assistive devices. Each participant will

Cash allowance programs are currently very small because they involve "state-only" funds.

develop a plan for the use of the cash. Funds can be carried over from month to month for large purchases or other personal care needs.

- Each state will determine the cash payment amount. States are generally planning to follow current assessment and care planning practices, establish the value of the individual care plan, and offer a cash amount based on the amount consumers would receive in the traditional program. The average monthly benefit in traditional programs varies greatly by state, as confirmed by the four demonstration states: Arkansas (\$320), Florida (\$389, weighted average for different programs), New Jersey (\$910), and New York (\$1,580 in state fiscal year 1996).

- Counseling services are an integral part of the demonstration. They will include services to help consumers decide whether to select the cash option and, for cash option participants, an

array of supportive services to help them manage employer responsibilities (such as hiring and training workers, arranging emergency backup, paying workers and employer taxes, etc.) or locate home modification subcontractors, etc. A fiscal intermediary service will be available to assist with accounting and payment tasks.

The evaluation is comprised of two components. The first is an experimental design in which *interested* consumers are randomly assigned to the cash option (treatment group) or the traditional services program (control group). The second is a process evaluation to study program implementation. The evaluation will compare outcomes for consumers in the treatment and control groups with respect to cost, quality, client satisfaction, and use of counseling services. The evaluation will also examine the impact of the cash option on formal and informal caregivers.

Among the many activities conducted during the project planning phase (e.g., completing a HCFA 1115 Research and Demonstration Waiver application to allow participants to receive cash payments and pay legally responsible relatives), the UMCA has been conducting background research that will guide program development and social marketing activities. Enrollment will begin sometime in 1999.

Assessing Consumers' Preferences for a Cash Option

Little research exists to indicate:

- how many consumers (or surrogate decision-makers) would choose a cash option;

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- what consumer characteristics might indicate who would choose cash vs. agency-based PAS; and

- what cash option features are attractive/unattractive to consumers and surrogates.

This information is essential to help the demonstration states design various cash option components (including counseling services) and social marketing approaches that will enable consumers and surrogates to make an informed choice between the cash option and their current program.

The demonstration states' communications and social marketing tasks are critical to achieving the CCDE's goals and are somewhat daunting for several reasons. As indicated by pre-survey focus groups, the cash option is quite different from traditional services and consumers often have difficulty understanding such a new and different concept. For consumers who have not completed high school, this communication effort is especially challenging. In addition, even those consumers who decide they like the cash option and feel qualified to try it will need to overcome fears and concerns about changing a service that is so important to their daily lives.

By their very nature, major social experiments push states to enroll many consumers (to have a sufficient sample size for hypothesis testing) during a relatively short period of time. Under the design proposed by Mathematica, New York has 1 year to enroll 3,750 current consumers from a population of approximately 65,000 clients (as reported in the period June–August 1996), plus 3,750 new consumers coming into the Medicaid program. Under current plans, two-thirds of all New York enrollees will be randomized to the treatment group that receives cash and one-third to the control group. Consequently, as mentioned earlier, the UMCA designed a three-part study to assess consumers' preliminary interest in a cash option. The RWJF provided funding to support this additional effort.

Consumers' Preferences for Consumer-Direction: Existing Research and Theory

Policymakers, program planners, and others have speculated that age would be a strong indicator of interest in a consumer directed model—i.e., younger consumers would be more likely to select a consumer-directed cash option. While research on consumers' preferences for consumer-

Consumers interested in the cash option were more likely to express a need for help or training in employer tasks.

directed services is limited, there is evidence that consumers of all ages—including elders—would like to be more involved in directing their care. In a small study of Minnesota home care clients (20 under age 65 and 34 over age 65), Eustis and Fischer (1992) found that while younger clients were more apt to take charge of their services, about one-third of older clients took charge of their care in at least three ways (e.g., participating in activities such as care plan development and hiring and training a worker.) Glickman, Brandt, and Caro (1994) surveyed 883 older Massachusetts home care clients to assess their interest in becoming more involved in managing their care. A substantial minority of clients said they would be willing to assume more responsibility in hiring, paying, scheduling, supervising, and firing their workers—ranging from a high of 39 percent willing to schedule their workers to a low of 24 percent willing to fire a worker.

In a study comparing 1,432 California home care clients in independent provider and agency contract models, Barnes and Southerland (1995) found that when consumers had the amount of management responsibility they wanted (regardless of their age), they were happier with their worker's reliability and quality of service. Doty, Kasper, and Litvak (1996) compared satisfaction with care among 879 older Medicaid personal care clients in three states (Michigan, Maryland, and Texas) with varying degrees of consumer direction. Clients were significantly more satisfied with their services in programs that permitted more consumer control.

In addition to limited knowledge regarding the impact of age on consumers' preferences for consumer direction, there is little information regarding other demographic and background characteristics that may influence interest in consumer direction. Glickman and colleagues (1994) provide some guidance—they found an association between client willingness to assume responsibility for directing a home care worker and the following client characteristics:

- prior experience directing an in-home worker,
- greater length of time receiving home care services,
- greater involvement in directing a home care worker, and
- lower levels of satisfaction with their home care services.

Research indicating differences in long-term care service use and care giving patterns among some minority groups—i.e., greater informal care and less nursing home use among some minority groups compared to their white counterparts—offers reason to speculate that preferences for consumer direction may differ among racial and ethnic groups (Tennstedt & Chang, 1998; Wallace, Levy-Storms, Kington, & Anderson, 1998; Rimer, 1998).

However, limited information about consumers' preferences for consumer direction, and specifically the cash option, point to the need to further understand many unanswered questions. Most importantly, what types of con-

sumers and surrogates, and how many, would choose the cash option given the opportunity? In addition, what would their reasons be for this choice?

Preference Study Design and Purposes

A three-part study consisting of presurvey focus groups, telephone surveys, and postsurvey focus groups was developed to:

- (1) determine preferences for consumer-directed services in general, and specifically for a cash option;
- (2) determine the percentage of consumers/surrogates choosing the cash option vs. traditional services;
- (3) identify reasons for consumers' / surrogates' preferences;
- (4) identify demographic and background characteristics of consumers/surrogates with specific preferences;
- (5) identify cash option features that are attractive/unattractive to consumers and surrogates;
- (6) identify what information consumers/surrogates need to decide whether to choose the cash option;
- (7) identify consumers' /surrogates' needs for counseling and support services; and
- (8) develop strategies to market the cash option.

We wanted to survey at least 382 of the 65,000 clients in New York who received personal care services between June and August of 1996. New York provided almost 4,200 randomly selected personal care client names and phone numbers to the University of Maryland Interdisciplinary Health Research Laboratory (IHRL) so they could be called and invited to participate. A 139-item valid and reliable questionnaire was developed to measure consumer and surrogate perceptions of the cash option, using items from other related surveys where appropriate as well as input from 11 different consumer and surrogate focus groups conducted in New York and Florida. (If you are interested in a full discussion of focus group findings, please see Zacharias [1997a, 1997b].) We also translated the survey into Spanish so Spanish speak-

ing consumers and surrogates could participate.

The survey consisted of four primary sections:

- satisfaction with current personal care services (27 items),
- perceptions regarding the cash option (33 items),
- demographic and background variables (44 items), and
- perceptions and demographics of surrogates (35 items).

Within these sections were four attitudinal subscales which measured satisfaction with worker characteristics, satisfaction with the availability of workers, overall satisfaction with personal care services, and willingness to assume more responsibility for one's care. To explain the cash option, interviewers read a scenario about a woman, Mrs. Green, who needed personal care services. The scenario described several different ways she could use her cash benefits. In addition, subsequent survey items informed respondents about various cash option features and support services. Background variables included a measure of functional status based on five activities of daily living (ADL's), an assessment of overall physical health, number of informal caregivers, and experience interviewing, training, hiring, or supervising workers.

Telephone interviews with New York Medicaid personal care recipients took place between April and June 1997. On average, interviews lasted 40 minutes. If consumers felt unable to answer survey items themselves, they provided the interviewer with the name and phone number of a surrogate responder. A series of questions were then asked of the surrogates to determine the type of decisions they helped consumers make (i.e., financial, medical, living arrangements, and medical).

Four hundred and ninety-three surveys were completed in New York, yielding a 23 percent response rate (493 completed surveys out of 2,181 eligible names). Of the almost 4,200 names and phone numbers New York provided, 600 were used in the pilot test, over 1,200 were unusable numbers (i.e., wrong locale, answering machine, busy

line, etc.), and almost 1,800 refused to participate. The primary reasons individuals gave for refusing to participate were:

- language barrier (33%: other than English, consumers were most likely to speak Spanish or Russian),
- no interest in completing any survey (16%), and
- feeling too sick, disabled, or old (15%).

Because of the large number of non-English speaking respondents, we calculated a second response rate where these individuals were excluded, resulting in a 32 percent response rate.

To determine whether respondents were similar to those who refused to participate, we compared a sample of these two groups on two items, age and dollars spent on services per year. There were no differences between responders and refusers in the amount spent on services; both groups averaged about \$15,500 per year in Medicaid personal care expenditures. However, on average, participants were younger than refusers, 69 years of age compared to 74 years.

Findings²

The majority of consumers were female (77%), had a high school education (39%) or less (35%), were 65 years of age or older (63%), lived alone (61%), and did not have experience hiring, firing, or interviewing workers (71%) or supervising or training workers (60%). Forty-six percent were widowed and 23 percent were single. Forty-seven percent were Caucasian, 31 percent were African American and 12 percent identified themselves as Hispanic. Seventy percent of consumers rated their overall health status as "fair" or "poor," while 28 percent rated it "good," "very good," or "excellent." A measure of functional status was obtained, based on the five ADL's (bathing, dressing, toileting, transferring, and eating). Individuals scoring between 0 and 1.5 were considered to be mildly disabled (52%), those scoring between 2 and 3.5 were considered moderately disabled (24%), and those scoring between 4 and

5 were considered severely disabled (24%).

Examination of the surrogate sample (n=105) revealed they were younger than consumers (82% were less than 65 years of age) and had higher levels of education (60% reported at least some college). Fifty percent were currently married and 60 percent reported they lived with a spouse or children. The majority of surrogates were relatives of consumers (83%) and female (65%). The racial/ethnic background of surrogates was similar to that of consumers.

Interest in the Cash Option

Approximately 40 percent (n=155) of consumers answering for themselves indicated interest in the cash option, with an additional 22 percent (n=85) indicating they were not sure of their interest (Table 1). When examining responses of surrogates who answered for consumers, 41 percent (n=37) thought the consumer would be interested and 19 percent (n=17) were not sure. Finally, surrogates were asked for their own opinion: 56 percent (n=58) liked the idea of the cash option, 15 percent (n=16) indicated they didn't know, and 28 percent (n=29) did not think it was a good idea. Overall then, 40 percent of consumers and 56 percent of surrogates were interested in the cash option.

Consumers differed in their interest in the cash option depending on their age, gender, and race/ethnicity. Fifty-five percent of consumers under age 65 were interested in the option, compared to 31 percent of those 65 and older. Likewise, a larger percentage of male respondents were interested in the option when compared to females, 57 percent versus 35 percent. Finally, more African American consumers were interested in the option (47%) when compared to Hispanic (39%) and Caucasian (36%) consumers.

We looked at other demographic and background variables to see if consumers who were interested in the option differed on these variables when compared to those who were not in-

	Interested N(%)	Not Sure N(%)	Not Interested N(%)
Consumer answering for him/ or herself ^a	155 (40.3)	85 (22.1)	145 (37.7)
Surrogate answering for consumer ^b	37 (40.7)	17 (18.7)	37 (40.7)
Surrogate answering for him/ or herself ^c	58 (56.3)	16 (15.5)	29 (28.2)

^aN = 385 ^bN = 91 ^cN = 103

Characteristic	Significance	Exponent (B) / Odds Ratio
Willingness to Assume Responsibility Subscale ^{**}	.0000	1.39
Satisfaction with Program Subscale ^{**}	.0000	.74
Desired Level of Involvement with Services	.0004	2.74
Gender	.0013	2.58
Race/Ethnicity	.0045	2.06

^{*}Exponent beta is used instead of an odds ratio with continuous variables
^{**}Continuous variable

terested. We found married consumers were most likely to be interested in the cash option (53% were interested) followed by separated (50%), single (48%), divorced (46%), and widowed (31%) consumers. Fifty-two percent of those who lived with a spouse or children and 50 percent of those who lived with a friend, partner, or relative indicated interest, compared with 34 percent of those who lived alone. Consumers who wanted more involvement with their current personal care services were more likely to be interested in the cash option (64%); when compared to those who wanted the same or less involvement, only 30 percent of these consumers were interested in the option. Consumers who had experience hiring, firing, or interviewing workers and those who had experience supervising or training workers were more likely to be interested in the cash option (64% and 56%); when compared with those

who did not have such experiences, only 33 percent and 31 percent, respectively were interested in the option.

Consumers who had an informal caregiver living with them were more likely to be interested in the cash option when compared to those who did not have an informal live-in caregiver: 55 and 40 percent respectively. Consumers who described their relationship with their personal care worker as "very close" were less likely to be interested in the option than those who described the relationship as other than "very close" (32% vs. 43%). For example, rather than reporting their relationship as "very close," they may have described it as an "employee-employer" relationship, "unfriendly," or even "hostile." Consumers who rated their disability level as "severe" were more likely to be interested in the option (53%) than those who rated their disability level as "moderate" (36% of

these consumers were interested) or "mild" (37% were interested).

Interest in the cash and counseling option was also related to how old the consumer was when he/she first acquired a disability. However, age of onset was also related to the consumer's current age, and when current age was controlled by looking at this relationship for each age group separately (those 65 and over and those 64 and under), age of onset of disability no longer affected interest in the cash option. There was a slight trend for those in the 65 and over age group who had acquired their disability before age 30 to be more interested in the option when compared to those 65 and older whose disability was acquired at a later age, but no similar trend was noted for the 64 and younger age group.

Consumer interest in the cash and counseling option did not differ by education, home ownership, presence or absence of informal caregivers, or current or former employment status. Similarly, interest did not differ by rating of overall health, number of personal care workers, number of new personal care workers in the past 12 months, length of time in the program (less than vs. greater than 3 years) or number of personal care workers dismissed (one vs. more than one).

Respondents were asked if they would be willing to sign up for the cash option even if due to randomization procedures there was a chance they might not get in. Of those interested in the option, 83 percent were still willing to sign up. Respondents were also asked if it would be more important to know the exact amount of money they would receive under the cash and counseling option or to know the amount was close to what the state now pays for their care. Fifty percent of those interested in the option thought it was more important to know the exact amount of money they would receive, compared to 33 percent of those not sure of their interest and 32 percent of those who were not interested.

Examination of the surrogate subsample (n=105) found their interest in the option differed by age, with surro-

gates 64 and younger more likely to be interested (58%) versus those 65 and older (50%). Surrogate interest also differed by race; 73 percent of the African American surrogates, 54 percent of Caucasian surrogates, and 50 percent of Hispanic surrogates stated they were interested in the option. Surrogate interest also differed by education—interest levels generally rose with level of education from less than high school (29% interested) to graduate degree (71% interested).

A multivariate analysis (logistic regression) was conducted to predict consumer interest in the cash option. Predictor variables included the demographic items race, age, education, and gender, the four attitude subscales,

and the significant predictors of interest identified via bivariate analyses presented above. Interest in the cash option was collapsed to test for differences between those who showed some interest in the option (i.e., "interested" and "not sure" respondents) versus those who showed no interest (the "not interested" respondents). The most important variable predicting consumers' interest in the cash option was the "willingness to assume responsibility" subscale (Table 2), which measured readiness to hire, train, schedule, pay, supervise, and fire one's own worker. Consumers' general satisfaction with their current personal care services (i.e., satisfaction with worker, schedule, and provider agency) was another important factor in

Table 3
Consumer and Surrogate Perceptions of the Importance of Cash Option Characteristics by Interest Level

CONSUMERS How important is it to:	Cash and Counseling Interest Level		
	Interested N (%)	Not Sure N (%)	Not Interested N (%)
<i>Hire Current Worker</i>			
Important	132 (69.1)	52 (51.5)	94 (52.8)***
Don't Know	15 (07.9)	29 (28.7)	27 (15.2)
Not Important	44 (23.0)	20 (19.8)	57 (32.0)
<i>Pay Worker More Money</i>			
Important	135 (71.4)	40 (40.0)	65 (37.4)***
Don't Know	27 (14.3)	42 (42.0)	45 (25.9)
Not Important	27 (14.3)	18 (18.0)	64 (36.8)
<i>Know a group of others who are participating</i>			
Important	137 (72.9)	57 (56.4)	51 (29.3)***
Don't Know	15 (08.0)	26 (25.7)	24 (13.8)
Not Important	36 (19.1)	18 (17.8)	99 (56.9)
<i>Be able to back out of cash option</i>			
Important	158 (84.0)	67 (65.7)	102 (58.3)***
Don't Know	13 (06.9)	27 (26.5)	26 (14.9)
Not Important	17 (09.0)	8 (07.8)	47 (26.9)
SURROGATES: How important is it to:			
<i>Hire Current Worker</i>			
Important	47 (81.0)	09 (56.3)	17 (58.6)***
Don't Know	02 (03.4)	06 (37.5)	01 (03.4)
Not Important	09 (15.5)	01 (06.3)	10 (34.5)
<i>Pay Worker More Money</i>			
Important	35 (60.3)	06 (37.5)	13 (44.8)***
Don't Know	10 (17.2)	08 (50.0)	03 (10.3)
Not Important	13 (22.4)	02 (12.5)	12 (41.4)
<i>Know a group of others who are participating</i>			
Important	43 (74.1)	07 (43.8)	05 (17.2)***
Don't Know	02 (03.4)	08 (50.0)	02 (06.9)
Not Important	13 (22.4)	01 (06.3)	21 (72.4)
<i>Be able to back out of cash option</i>			
Important	55 (94.8)	11 (68.8)	17 (58.6)***
Don't Know	00 (00.0)	05 (31.3)	02 (06.9)
Not Important	03 (05.2)	00 (00.0)	09 (31.0)

*** p < .001

Table 4
Consumers Who Want Help or Training with Task by Cash and Counseling Interest Level

Would you want help or training with any of the following tasks?	Cash and Counseling Interest Level		
	Interested N (%)	Not Sure N (%)	Not Interested N (%)
<i>Finding a worker</i>			
Yes	119 (62.0)	54 (54.0)	78 (45.6)***
Don't Know	13 (06.8)	21 (21.0)	24 (14.0)
No	60 (31.3)	25 (25.0)	69 (40.4)
<i>Interviewing a worker</i>			
Yes	98 (51.0)	48 (47.5)	78 (45.1)***
Don't Know	06 (03.1)	16 (15.8)	13 (07.5)
No	88 (45.8)	37 (36.6)	82 (47.4)
<i>Doing a background check</i>			
Yes	138 (72.6)	59 (58.4)	92 (53.5)***
Don't Know	07 (03.7)	18 (17.8)	08 (04.7)
No	45 (23.7)	24 (23.8)	72 (41.9)
<i>Deciding how much to pay a worker</i>			
Yes	146 (76.4)	63 (61.8)	91 (52.9)***
Don't Know	05 (02.6)	19 (18.6)	15 (08.7)
No	40 (20.9)	20 (19.6)	66 (38.4)
<i>Knowing what to do if a worker didn't show</i>			
Yes	125 (65.4)	63 (61.8)	91 (52.9)***
Don't Know	7 (03.7)	15 (14.7)	14 (08.1)
No	59 (30.9)	24 (23.5)	67 (39.0)
<i>Firing a worker if necessary</i>			
Yes	84 (44.2)	53 (52.0)	87 (50.6)***
Don't Know	05 (02.6)	16 (15.7)	14 (08.1)
No	101 (53.2)	33 (32.4)	71 (41.3)
<i>Payroll and taxes</i>			
Yes	149 (78.0)	64 (62.7)	84 (48.6)***
Don't Know	04 (02.1)	16 (15.7)	18 (10.4)
No	38 (19.9)	22 (21.6)	71 (41.0)

Note: N may vary slightly due to missing data *p < .05 **p < .01 ***p < .001

predicting interest. Consumers with lower satisfaction scores were more likely to be interested in the cash option.

Consumers' desired level of involvement with their personal care services also predicted interest in the option. Those who wanted more involvement in determining the amount and type of services they currently receive were almost three times as likely to be interested in the option when compared to those who wanted the same or less involvement with their current services. The next most important variable, which predicted interest, was gender. Males were about two and a half times as likely to be interested in the option as females, although this could partially be due to age, as female respondents were more likely to be 65 or older when compared to males. Finally, African American consumers were twice as likely to be interested in

the option as white or Latino consumers. These five factors (Table 2) predicted with 85 percent accuracy consumers who were either interested or not sure of their interest in the cash option and with 62 percent accuracy those who indicated they were not interested (overall 76% accuracy). No other factors or combination of factors were found to significantly improve upon this prediction rate.

Attractive Program Features and Services Consumers Want to Purchase

Consumer and surrogate ratings of the importance of various program characteristics differed by level of interest in the cash option for each of four program characteristic items. Interested consumers were more likely than those not interested to consider it important

to be able to hire their current worker (69% vs. 53%), pay their worker more money than he/she currently receives (71% vs. 37%), back out of the cash option if they desired (84% vs. 58%), and know a group of other consumers participating in the option (73% vs. 29%) (Table 3). Similar differences were found between the interested and not interested surrogates (Table 3). Differences were also found by age when examining the importance of these program characteristics to consumers and surrogates. Consumers 64 and younger were more likely than those 65 and older to consider each characteristic important. For surrogates, those 64 and younger were more likely than the older group to consider it important to know other participating consumers.

Consumers were also asked whether particular program characteristics would make them interested in the cash option. Features they were specifically asked about included the ability to "get services on the days and times you want them," "hire whomever you wanted to provide services, even a friend or relative," and "use the money to buy different services or make home modifications." Eighty-nine percent of those interested in the option stated each of these features contributed to their interest in the option. These same characteristics were appealing to only 14 to 19 percent of the consumers not interested in the option.

Surrogates were also asked a series of questions to determine reasons for their interest in the cash option, and surrogates interested in the option were much more likely to be interested in these specific characteristics when compared to those not sure of their interest and those not interested. Anywhere from 74 to 88 percent of surrogates interested in the option agreed with the various items, compared to just 3 to 17 percent of those not interested. To elaborate, the majority of interested surrogates agreed the cash option would offer more flexibility to both the consumer (88%) and themselves (86%). They also liked the idea of being able to interview and hire the worker (83%) and being able to hire a friend or relative (74%). In addition, 74

percent of the interested surrogates believed the consumer would like to participate in the option.

Finally, surrogates were asked if they thought the cash option would make it easier or harder on them; 32 percent believed the option would make their job easier while 37 percent thought it would be harder. However, again, those surrogates interested in the option were much more likely to think it would make their job easier (55%) when compared to the not sure and not interested groups. Also, interested consumers were more willing to take on the tasks related to managing personal care workers (like scheduling, hiring, and supervising, among others).

Respondents were asked about their interest in purchasing various services, including more hours of personal care service; grab bars or equipment to help in the shower; wheelchair, motorized scooter, hospital bed, or chair lift; home remodeling services; exercise equipment; transportation services; laundry services; and housekeeping services. Again, those interested in the cash option were much more likely to want to purchase the various services when compared to those not interested or those not sure of their interest level. The services a majority of the respondents interested in the option wanted to purchase included more hours of service (66%), wheelchairs or other equipment (52%), and transportation services (65%).

Consumers 64 and younger were more likely than those 65 and older to be interested in purchasing more hours of service (52% vs. 39%), grab bars or shower equipment (36% vs. 21%), home remodeling service (29% vs. 11%), exercise equipment (28% vs. 16%), and transportation services (55% vs. 35%). The two age groups did not differ in their interest in purchasing wheelchairs or other equipment.

Consumer and Surrogate Training and Support Needs

Seven different tasks associated with the cash option were included in the survey and the majority of consumers wanted assistance or training in each of

Table 5
Surrogate Need for Help or Training with Task by Cash Option Interest Level

Would you want help or training with any of the following tasks?	Cash and Counseling Interest Level		
	Interested N (%)	Not Sure N (%)	Not Interested N (%)
<i>Finding a worker</i>			
Yes	44 (75.9)	08 (50.0)	11 (37.9)***
Don't Know	00 (00.0)	05 (31.3)	01 (03.4)
No	14 (24.1)	03 (18.8)	16 (55.2)
<i>Interviewing a worker</i>			
Yes	26 (44.8)	07 (43.8)	09 (31.0)
Don't Know	00 (00.0)	02 (12.5)	01 (03.4)
No	32 (55.2)	07 (43.8)	18 (62.1)
<i>Doing a background check</i>			
Yes	46 (79.3)	11 (68.8)	12 (41.4)*
Don't Know	01 (01.7)	01 (06.3)	01 (03.4)
No	11 (19.0)	04 (25.0)	15 (51.7)
<i>Deciding how much to pay a worker</i>			
Yes	45 (77.6)	10 (62.5)	10 (34.5)***
Don't Know	02 (03.4)	03 (18.8)	01 (03.4)
No	11 (19.0)	03 (18.8)	17 (58.6)
<i>Knowing what to do if a worker didn't show</i>			
Yes	41 (70.7)	08 (50.0)	10 (34.5)**
Don't Know	00 (00.0)	02 (12.5)	01 (03.4)
No	17 (29.3)	06 (37.5)	17 (58.6)
<i>Firing a worker if necessary</i>			
Yes	24 (41.4)	03 (18.8)	07 (24.1)
Don't Know	01 (01.7)	01 (06.3)	02 (06.9)
No	33 (56.9)	11 (68.8)	19 (65.5)
<i>Payroll and taxes</i>			
Yes	50 (86.2)	10 (62.5)	12 (41.4)**
Don't Know	00 (00.0)	01 (06.3)	01 (03.4)
No	08 (13.8)	04 (25.0)	15 (51.7)

Note: N may vary slightly due to missing data *p < .05 **p < .01 ***p < .001

these areas. However, those interested in the cash option were more likely to want help or training on each task when compared to the other two groups (Table 4). They were more likely to want help with payroll taxes (78%), deciding how much to pay a worker (76%), doing a background check on a worker (73%), what to do when a worker doesn't show (65%), finding a worker (62%), interviewing a worker (51%), and firing a worker (44%). For those not sure of their interest in the cash option, the need for help or training was most acute for assistance with payroll taxes (63%), followed by what to do when a worker doesn't show (62%), and deciding how much to pay a worker (62%) (Table 4). For those not interested in the cash option, the largest percentage believed they would need help doing a background check (54%), followed by determining what to do

when a worker didn't show (53%), and deciding how much to pay a worker (53%) (Table 4). When comparing consumers by age group, those 65 and older were more likely to indicate the need for help or training with interviewing a worker while those 64 and younger were more likely to want help doing a background check on a worker.

Examination of surrogates' perceptions, when they were answering for themselves (n=103), found differences by interest level in need for help or training on 5 of the 7 tasks. Surrogates interested in the cash option, versus those not certain and those not interested, were more likely to indicate a need for help or training with payroll taxes (86% vs. 63% vs. 42%) (Table 5). They were also more likely to want help or training doing a background check on a worker (79% vs. 69% vs. 41%), deciding how much to pay a

worker (78% vs. 63% vs. 35%) finding a worker (76% vs. 50% vs. 38%), and knowing what to do when a worker doesn't show (71% vs. 50% vs. 35%) (Table 5).

Overall, before deciding to be involved in the cash option, the majority of consumers (regardless of their interest level) wanted more information. However, respondents were even more likely to want additional information if they were interested in the option or not certain of their interest. Specifically, when asked if they needed to know more financial details, 94 percent of those interested, 96 percent of those not sure, and 54 percent of those not interested answered "yes" (overall 80%). When asked if they needed to know whether their current worker could be retained, 84 percent of those interested, 84 percent of those not sure, and 69 percent of those not interested responded "yes" (overall 79%). When asked if they needed to know how other current benefits they receive would be affected, the percentage breakdown was 99 percent, 93 percent, and 72 percent respectively (overall 88%). Finally, when asked if they needed to know more about their rights and responsibilities under the cash option, 98 percent of the interested consumers, 98 percent of those not sure, and 71 percent of those not interested responded "yes" (overall 88%).

Discussion and Recommendations

Survey results will guide New York in designing numerous aspects of the cash and counseling demonstration; however, this discussion will focus on the implications of survey findings for New York's critical communications and social marketing efforts. Survey data will help provide answers to three broad questions:

- How can New York reach those consumers and surrogates most interested in the cash option?
- What messages should New York emphasize in its communications and social marketing efforts?

- What issues need to be explored further in the postsurvey focus groups?

Targeting Interested and Uncertain Consumers and Surrogates

Frequency data obtained in this survey can clearly guide New York's social marketing efforts. Findings indicate that New York should be able to achieve evaluation enrollment targets by focusing on those individuals who indicated an initial interest in the cash option (40% of responding consumers). In addition, 21 percent of consumers were unsure of their initial interest in the cash option. New York will need to use data from the survey and followup focus groups to learn more about what information is needed to help the "unsure" population make a well-informed decision to choose the cash option or stay with their current program. Also, knowing that 35 percent of respondents had less than a high school education and 39 percent had not gone beyond a high school education serves as a reminder that outreach and training materials must be simple and straightforward (and/or many consumers may need the assistance of surrogates and direct contact with counselors).

We found that males were more interested in the cash option than females (57% vs. 35%). In addition, African Americans were more interested than Latinos and Caucasians (47%, 39%, and 36% respectively). However, the vast majority of the New York sample was female (77%) and was about equally divided between Caucasians (47%) and African Americans and Latinos combined (43%). So, although more males and African Americans are interested in the option, females and Caucasians are more prevalent in the consumer population. Therefore, New York program officials need to learn more about which cash option features are appealing to women and Caucasians, which was addressed during the postsurvey focus groups. These discussions were designed to learn more about the reasons

behind consumers' preferences as they vary by race and gender.

One of the survey's major research questions inquired about age as a factor influencing interest in the cash option; we found younger consumers to be more interested than elders (55% vs. 31%). However, a sizable minority of elders were interested in the cash option. This information guides New York to include both age groups in social marketing efforts; however, program workers need to focus on reaching the

Limited information about consumers' preferences for consumer direction, and specifically the cash option, point to the need to further understand many unanswered questions.

younger group (who make up a smaller proportion of consumers receiving services in New York) and learning more about factors that would help uncertain elders feel comfortable with the cash option.

Two other key factors require further exploration to guide social marketing efforts. Survey data indicate the highest level of interest in the cash option—56 percent—is among surrogate decision makers when expressing their own views. In addition, consumers who live with their informal caregiver are more interested in the cash option than those without this arrangement. It is possible these two variables are related, as the surrogate decision maker is likely to be an informal caregiver. New York needs to learn more about the reasons for surrogates' high level of interest in the cash option, as well as their role in working with a consumer to choose the cash option. The same is true for the role of a live-in informal

caregiver: How does the presence of this individual influence a consumer's decision to select a cash option? One possible explanation is that the informal caregiver could serve an emergency backup role if the paid worker doesn't come to work—an important concern expressed by consumers. Without support from informal caregivers, many consumers may lack the confidence to take on the additional responsibilities required in the cash option. Another explanation may be that the consumer would want to hire the informal caregiver as a paid worker. Further understanding of the surrogate and informal caregiver roles can help New York develop social marketing messages that address high levels of interest among surrogate decision makers and consumers with a live-in informal caregiver.

Communications and Social Marketing Messages to Emphasize

Two consumer attributes that strongly predicted interest in the cash option were consumers' willingness to perform employer tasks needed to direct their own care and consumers' desire to be more involved in determining the amount and types of services they receive. At first glance, these two characteristics may appear to be quite similar, and possibly proxy indicators for interest in the cash option. However, closer scrutiny illuminates possible differences between these two attributes. Some consumers may want more say in the types and amounts of services they receive and at the same time be unwilling to conduct some or all employer tasks needed to direct their own care. For example, they may feel strongly about being able to specify key aspects of their service (e.g., who provides what service, when, and how much) and want others to carry out some or all of their wishes. Their desire for more involvement may boil down to a desire to assess their own needs and (help) develop a plan which others can implement, as opposed to a wish to carry

out employer tasks such as hiring and paying a worker. Once again, the post-survey focus groups were designed to further explore these concepts.

Surrogates' interest in the cash option was also related to their willingness to assume responsibility for employer tasks—a concept to highlight in social marketing materials. In addition, surrogates' interest in the cash option was related to a belief that this option would make it easier on them. Among interested surrogates, even those who thought the cash option would be harder believed their extra effort would be worthwhile. Knowing this, the post-survey focus groups explored how the cash option could be easier for surrogates and, if extra effort would be required, which specific aspects make the exertion worthwhile.

Cash option characteristics attractive to interested consumers provide further direction regarding social marketing messages and, more importantly, direction for designing the cash option. For example, effective materials would address the ability to "get services on the days and at the times you want" and "hire whomever you want to provide personal care services, even a friend or a relative," as the vast majority of interested consumers found these program characteristics appealing. The attractiveness of being able to hire one's own worker is consistent with the finding that consumers who described their relationship with their personal care worker as "very close" were less likely to be interested in the option when compared to those who described the relationship as other than "very close." As the survey addressed the possibility of hiring "a friend or a relative," the followup focus group discussion differentiated between either a friend or relative to learn if consumers find one more appealing than the other. Presurvey focus groups indicated some negative feelings about hiring relatives. Finally, interested consumers also found the ability to "buy different services" an attractive program feature.

Surrogates' reasons for being interested in the cash option also offer messages to include when addressing that

group. Materials should definitely highlight the ability to interview and hire workers, increased flexibility for consumers and surrogates, and the cash option's potential benefits for the consumer.

Consumers and surrogates provided consistent information regarding cash option features they found attractive, providing further direction about messages to include in social marketing materials for both groups. Consumers and surrogates who were interested in the cash option were most likely to think it was important to have peer support from others in the cash option. They also wanted to know that, should they feel the need or want, they could pay their worker more than the worker currently receives and that they could back out of the cash option if they wanted to return to the traditional program. There were differences between older and younger consumers regarding the importance of these features, with consumers under 65 more likely to consider each feature important.

Finally, interested consumers and surrogates considered it important to be able to hire their current worker should they choose the cash option. This information is a strong message that the state needs to address this difficult issue in its social marketing efforts. Presurvey focus group participants frequently described problems with former workers and explained that when they had a worker they liked they wanted to continue with that person. Yet, difficult organizational issues are likely to interfere with this consumer preference. Most important, provider agencies and/or union contracts may limit this practice. In addition, a worker may need full-time employment and only work part-time hours for a specific consumer. This issue is likely to be less important for new consumers entering the Medicaid program, as they would be less attached to an existing arrangement.

Consumers interested in the cash option were more likely to express a need for help or training in employer tasks. Social marketing materials should inform consumers they can have help or training with the most requested tasks,

which included: payroll taxes, help deciding how much to pay a worker, doing a background check on a worker, and what to do when a worker doesn't show, as well as finding, interviewing, and firing a worker. Older and younger consumers differed only slightly regarding their need for training or help, indicating minimal need to address this issue differently by age groups. Social marketing materials should inform surrogates they can have help or training with the same tasks; however, materials would highlight a slightly different order to reflect the priorities of surrogates interested in the cash option: i.e., help or training with payroll taxes, doing a background check, deciding how much to pay a worker, finding a worker, what to do when a worker doesn't show, as well as interviewing and firing a worker.

As the majority of consumers wanted more information before deciding whether to choose the cash option, social marketing materials and in-person communication should be as specific as possible regarding the following issues (listed in order of importance):

- how other current benefits would be affected,
- consumers' rights and responsibilities under the cash option,
- cash option financial details, and
- how the current worker would be affected.

When survey respondents were asked whether it was more important to know the exact amount or that the amount was close to what the state now pays the agency, half of those interested in cash thought it was more important to know the exact amount. It was therefore important to test materials explaining the financial details in the postsurvey focus groups.

Cash and counseling project planners have had some concern about the difficulty of explaining randomization to consumers and the possibility that randomization would be a deterrent to choosing the cash option. Survey findings dispel these concerns to a large degree, as 83 percent of those interested in the cash option were willing to

sign up even if there was a chance they might not be selected. However, it was important to test materials explaining randomization during the postsurvey focus groups to be sure they were clearly understood.

Six additional issues were explored in the New York followup focus group discussions.

Although 40 percent of all respondents expressed a preliminary interest in the cash option (a sizable amount), the remaining were uncertain or not interested.

First, successful communications and social marketing efforts depend on knowing the sources of credible (and unreliable) information for consumers and surrogates. For example, should social marketing efforts utilize certain well-regarded community organizations?

Second, it was very important to test draft materials to be sure they would be effective for a population primarily comprised of people with a high school education or persons not completing high school.

Third, the timing of presenting various issues was also important to test. For example, what messages are critical "door openers" to be included in general introductory materials? What information should be included in followup communication?

Fourth, it was necessary to learn when consumers/surrogates wanted hands-on assistance as opposed to training that would allow them to function independently. Specifically, the focus groups assessed consumers' and surrogates' views about the fiscal intermediary role.

Fifth, New York needed to determine if it would be necessary and/or feasible to develop separate materials for specific segments of the population (i.e., according to gender, race, age, surrogate or consumer viewpoint, etc.). Although this question is related to resources and deadlines, it was tested in the focus groups.

Sixth, given that "language barrier" was identified as the primary reason for refusing to participate in the survey, language needs must be addressed. The focus groups were designed to assist New York in developing and translating materials for non-English speaking participants.

Policy Issues

The CCDE is a policy-driven project addressing numerous policymaker concerns. While comprehensive recommendations will not be available until the evaluation is complete, the New York preference survey offers insight into policy issues concerning the importance of offering consumers a choice of PAS options, as well as insights regarding potential fraud and abuse and service quality concerns.

The CCDE is based on the premise that the cash option is a *choice* available to those consumers who want consumer direction. It is not intended to replace traditional services, as the cash option is unlikely to be appropriate for or desirable to all consumers. The New York survey findings support this perspective. Although 40 percent of all respondents expressed a preliminary interest in the cash option (a sizable amount), the remaining were uncertain or not interested.

Fraud and abuse concerns relate to the possibility that consumers and/or their families might misuse the cash benefit or be exploited by others (Doty, 1997). While the demonstration must and will address these concerns, procedures to minimize fraud and abuse must also maintain the consumer empowerment principles being tested in the CCDE. Overly restrictive measures could negate the effect of the consumer-directed intervention.

Misuse of the cash benefit includes the possibility that consumers might not pay taxes for their workers. New York survey data indicate these possibilities are limited, as a majority of consumers and surrogates interested in the cash option (78% and 86%, respectively) said they would want help or training

monitoring all consumers—including those with surrogates.


For those consumers functioning independently (without surrogates), the cash option training and support services offer further protection against consumer exploitation. When asked whether they would want help or training with various cash option tasks, the majority of consumers were interested in these support services, especially those that expressed interest in the cash option.

New York survey respondents found the ability to “hire whomever you want to provide personal care services, even a friend or relative,” an attractive feature of the cash option. This finding indicates that many consumers are likely to hire friends or relatives as their workers. Policymakers often raise concerns about the quality of care provided by friends or relatives, as they may lack formal training. Yet, two studies of California’s In-Home Support Services program (Barnes & Sutherland, 1995; Benjamin, Mathias, & Franke, 1998) found that consumers rated family members and friends as more reliable than workers who were strangers. In addition, a study of elderly Medicaid personal care recipients in Michigan found that client satisfaction was related to several indicators of greater client control and, specifically, to Michigan’s policy of encouraging clients to hire family, friends, and neighbors as attendants (Doty, Kasper, & Litvak, 1996). The CCDE will further our understanding about the quality of services when friends and relatives become paid providers.

In regard to the research question about consumers’ age as an indicator of interest in the cash option, it is important to assess this question on an ongoing basis as aging baby boomers—the next generation of elders—are likely to be more interested in consumer direction than today’s older population. While the New York survey found 31 percent of elders are interested in the cash option, younger consumers were 1.32 times as likely to be interested as elder consumers. This trend could shift in coming years as baby boomers have grown up with the consumerism movement and they will most likely carry

this perspective into their later years. This trend may be especially true for the next generation of elders who have aged with a disability. Many baby boomers that have had early onset disabilities have grown accustomed to independent living principles and they are likely to want to continue directing their care as they age. The survey data hint at this possibility, as there was a slight trend for consumers over age 65 who had acquired their disability before age 30 to indicate a greater interest in the cash option than elders who acquired a disability at a later age.

Summary

This article has presented results from a telephone survey conducted to assess consumers’ preferences for a cash option vs. traditional services in New York, one demonstration state in the CCDE. The telephone survey was conducted as background research to guide project development. Survey findings will guide New York in designing the cash and counseling option and developing much needed communications and social marketing materials. These efforts are essential to informing New York consumers about the cash option so they can make informed decisions to choose a consumer-directed option or stay in the traditional program. The authors look forward to continued learning about consumers’ interest in and satisfaction with a cash option (vs. traditional services) when the demonstration is implemented and the choice becomes real, not theoretical. 

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For those consumers functioning independently (without surrogates), the cash option training and support services offer further protection against consumer exploitation.

with payroll and taxes. More precisely, most clients are likely to elect to have these services performed by accounting professionals. This would greatly reduce the amount of cash consumers actually need to manage (Doty, 1997). Those consumers electing not to use accounting professionals will need to participate in a training program and demonstrate the skill to handle payroll tasks.

To prevent consumer exploitation by others (and subsequent suffering of ill effects), the cash option allows/encourages the use of surrogate decision makers to represent consumers who are unable to make all decisions independently. While there are many questions to consider regarding surrogate decision makers, we know from the New York survey that 21 percent of consumers used surrogates and that 56 percent of these surrogates, when responding for themselves vs. representing a consumer, were interested in the cash option. In the event of possible exploitation by a surrogate, it is important to note that under the cash option counselors will have a role in mon-

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Notes

1. Much of this section comes from background materials written by Pamela Doty, the CCDE's project officer at DHHS/ASPE, during the project development phase.

2. For a more detailed discussion of procedures and statistical analyses, please refer to the full New York State report, entitled "Determining Consumers' Preferences for a Cash Option: A Report on New York Telephone Survey Findings."

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NEW PUBLICATIONS AND FILMS

The Osteoporosis Solution. New Therapies for Prevention and Treatment.

Carl Germauo, RD, CNS, LDN, with William Cabot, M.D. Kensington Publishing Corp., 850 Third Avenue New York, NY 10022. Hardcover, 203 pages, \$22.00. <<http://www.kensingtonbooks.com>>

The latest developments in nutritional therapies are outlined and explained in this guide that also offers a step-by-step plan for building and maintaining healthy bones with a new class of dietary supplements and the foods we eat. There is also information on the importance of exercise, and the extraordinary link between your bones and your immune system—a crucial element in understanding and preventing this disease.

American Medicine: The Quest for Competence.

Mary-Jo DelVecchio Good. University of California Press, 2120 Berkeley Way, Berkeley, CA 94720. Telephone: (510) 642-4247. Softcover, 265 pages, \$16.95.

Based on three research studies, this book discusses the meaning of physician competence in medical practice, medical politics, and medical education in the United States in the late 20th century and examines the following questions: How should doctors be trained to attain the highest standards of medical competence, in particular without losing essential "caring" qualities expected by the public? How should the profession sustain and enhance the competence of its members in the face of extraordinary transformations in biomedical knowledge and technologies? Why, when the science of medicine appears most advanced, does the political and economic organization of medical practice appear to threaten "good doctoring," collegial relationships, and adequate care of patients? Who should have the authority to decide requisite competencies in

medical work and determine specialty boundaries? What should the profession's response be to rising costs of medical liability, intermittent malpractice crises, and collective responsibility for limiting harm to patients? How can the quality of medical knowledge, practice, and care be preserved when the financing and delivery of health-care and the very institutions of our medical commons are in turmoil?

Dr. Gaynor's Cancer Prevention Program.

Mitchell L. Gaynor, M.D., and Jerry Hickey, R.Ph. Kensington Publishing Corp., 850 Third Avenue New York, NY 10022. Hardcover, 316 pages, \$24.00. <<http://www.kensingtonbooks.com>>

The author believes that the primary answer to cancer lies in preventing it before it starts; his book illustrates how to incorporate the guidelines developed in his clinical practice into your personal health plan. This book includes detailed information about anti-cancer foods and supplements, as well as protocols for preventing such specific cancers as breast, prostate, gastrointestinal, and lung.

Don't Snore Anymore. Your Complete Guide to a Quiet Night's Sleep.

Jeffrey N. Hausfeld, M.D. Three Rivers Press, 201 E. 50th St., New York, NY 10022. Telephone: (212) 572-2537. FAX: (212) 572-2537. <<http://www.randomhouse.com>> Softcover, 214 pages, \$12.00.

Written by one of the nation's foremost pioneers in the treatment of snoring and sleep-related breathing disorders, this book reveals the most recent discoveries of medical science about the causes and treatments of snoring, including at-home treatments, over-the-counter products, and Dr. Hausfeld's innovative laser technique that he has taught to thousands worldwide.

A compendium of two decades of clinical expertise and experience treat-

ing tens of thousands of patients, this book should prove a comprehensive resource to bring hope and help to the nation's 40 million snorers and their loved ones.

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Symptom Management in Multiple Sclerosis. 3rd Edition.

Randall T. Schapiro, M.D. *Demos Vermande*, 386 Park Avenue South, Suite 201, New York, NY 10016. Toll-Free Telephone: 1-800-532-8663. Softcover, 204 pages, \$19.95 plus \$4.00 for shipping and handling.

Management strategies for multiple sclerosis fall into two general categories—those used to treat the underlying disease process and those used to minimize and control specific symptoms such as spasticity, bowel or bladder problems, or fatigue. This volume focuses on the management of specific symptoms that may develop as the result of the disease process in multiple sclerosis. It is based on the management program developed at The Fairview Multiple Sclerosis Center in Minneapolis.

Wheelchair Selection and Configuration.

Rory A. Cooper, Ph.D. *Demos Medical Publishing, Inc.*, 386 Park Avenue South, Suite 201, New York, NY 10016. Telephone: (212) 683-0072. Softcover, 424 pages, \$34.95.

A definitive text for everyone concerned with wheelchair selection, including physical and occupational therapists and other healthcare providers involved with helping patients to achieve optimal seating. Chapters discuss wheelchair measurement, engineering fundamentals, biomechanics, electronics, and standards. Various types of wheelchairs are considered, including manual, powered, specialized, and sports chairs; the selection of seat cushions and specialized seating systems are considered in depth and assessment and intervention are reviewed.

The Complete Learning Disabilities Directory. 6th Edition.

Grey House Publishing, Pocket Knife Square, Lakeville, CT 06039. Toll-Free Telephone: 1-800-562-2139. Softcover, 642 pages, \$130.00 plus \$10.00 shipping and handling.

This sixth edition now has over 6,500 entries, detailing LD associations and organizations; schools, colleges, and learning centers; assistive devices and computers; books, tapes, and periodicals; government agencies; and camps and summer programs. With a wealth of information not found in previous editions, this directory may be the most comprehensive resource for individuals with learning disabilities. The Entry and Subject Indexes have been completely updated and a new Geographic Index has been added.

Spinal Cord Injury: An Analysis of Medical and Social Costs.

Monroe, Berkowitz, Paul K. O'Leary, Douglas L. Kruse, and Carol Harvey. *Demos Medical Publishing, Inc.*, 386 Park Avenue South, Suite 201, New York, NY 10016. Telephone: (212) 683-0072. Hardcover, 208 pages, \$89.95.

This volume expands and updates information previously presented in *The Economic Consequences of Traumatic Spinal Cord Injury* and reports results from a new survey of the costs of spinal cord injury (SCI). It explores the elements that make up both the medical and nonmedical direct costs of SCI, focusing specifically on the costs of home modifications, vehicle adaptations, and wheelchairs. It also focuses on the determinants of employment for persons with SCI.

Coping with Blindness. Personal Tale of Blindness Rehabilitation.

Alvin Roberts. *Southern Illinois University Press*, P.O. Box 3697, Carbondale, IL 62901. Telephone: (618) 453-6633. Softcover, 123 pages, \$12.95.

Sightless himself and a veteran of four decades of helping people cope with blindness, Alvin Roberts decided that telling stories drawn from the community of the blind and from his fellow rehabilitation workers was the best way to reassure others—especially the elderly, who are most at risk of becoming visually impaired—that “blindness need not be the end of active life, but rather the beginning of a life in which

[people] will depend on their residual senses to continue full active living.”

As the reader soon learns, Roberts is a skilled raconteur. Very skilled. He arms himself with the full arsenal of the storyteller's tricks—drama, irony, action, traces of tall tale, and humor—especially humor. He tells unsentimental stories about how blind people face their affliction and eventually cope with it. The stories are based on the author's experience, that of people he has met and worked with, and that of his coworkers.

Roberts shows that there is competent help for visually impaired persons. And he shows that there is hope for a full life. He paints a positive picture of what it is like to be blind, replacing fear, dread, and myth with reality.

Alvin Roberts is the regional administrator for the Bureau of Blind Services in Carbondale, Illinois. He has more than 40 years experience as a rehabilitation teacher of the blind. He is the author of *Psychological Rehabilitation of the Blind* and a book of short stories, *Tavern Tales*.

New Frontiers in Psychosocial Occupational Therapy.

Anne Hiller Scott, editor. *The Haworth Press, Inc.*, 10 Alice St., Binghamton, New York, NY 13904-1580. Toll-Free Telephone: 1-800-429-6784. E-mail: <getinfo@haworthpressinc.com> Hardcover, 176 pages, \$29.95.

Articles in this publication explore plans and processes to improve patient care through enhanced therapist/patient relationships and strong alliances with mental health advocate groups. In addition to articles written by therapists, patients, and occupational therapy educators, this text features several students' personal accounts of their fieldwork experiences and how they overcame the fear of inadequacy, learned additional procedural skills in occupational therapy assessment, became comfortable with group leadership, and, as a result, learned the importance of patient/practitioner relationships as they relate to improved services.

Disability Management Conference Scheduled

The Thirteenth Annual National Disability Conference & Exhibit, "Rehearsing Your Future: Healthy People, Healthy Companies," will be held October 27-29, 1999, at JW Marriott in Washington, DC. Presented by The Washington Business Group on Health, the conference will be sponsored by the UNUM Life Insurance Company of America. For more information contact Ann Makowski, WBGH, 777 N. Capitol St., NE, Suite 800, Washington, DC 20002. Telephone: (202) 408-9320 (voice), (202) 408-9332 (Fax). E-Mail: <makowski@wbgh.com>.

1998-1999 Guide to Toys for Children Who Are Blind or Visually Impaired

The American Foundation for the Blind (AFB) and Toy Manufacturers of America (TMA) have released the latest edition of the highly successful *Guide to Toys for Children Who Are Blind or Visually Impaired*.

The guide is a one-of-a-kind resource for parents, grandparents, and teachers that contains commercially available toys and games appropriate for children of all ages who are blind, have low vision, or have multiple impairments that include visual impairment. It is also useful for adults with visual impairments who wish to participate in play with sighted children. It features 100 new toys—with an emphasis on multimedia and interactive toys—in a wide price range. Of note is an introductory section that makes it easier for adults choosing toys to understand the selection criteria used and shows readers how to apply these criteria beyond the products appearing in the guide.

Single copies and supplies of the guide are available in full-color print or on audio cassette free of charge by contacting the American Foundation for the Blind, 11 Penn Plaza, Suite 300, New York, NY 10001. Telephone: 1-800-232-5463; or Toy Manufacturers of America, 200 Fifth Avenue, Room 740, New York, NY 10010. Fax: (212) 633-1429.

"There are nearly 10 million people of all ages who are blind or visually impaired in the U.S. today," said Elga Joffe, Director, AFB Information Center, "and thus there is a tremendous need for the information and guidance provided by the guide. It educates families, friends, and teachers that visually impaired children enjoy a wide variety of toys."

Ms. Joffe added that the many new multimedia toys on the market means that there are more choices for visually impaired children and their parents, and the guide can be invaluable in helping to select toys that offer both strong play value and developmental and educational benefits.

Children from New York metropolitan-area summer programs for blind students participated in the toy evaluation sessions, and AFB Talking Books donated the recording and production of the guide on audio cassette so that it is accessible to people who are blind or visually impaired.

The American Foundation for the Blind—the organization to which Helen Keller devoted more than 40 years of her life—is a national, nonprofit organization whose mission is to enable people who are blind or visually impaired to achieve equality of access and opportunity that will ensure freedom of choice in their lives. AFB is headquartered in New York City and maintains offices in Atlanta, Chicago, Dallas, and San Francisco, and a governmental relations office in Washington, DC.

Second International Social Role Valorization Conference to be Held in Boston

"Creating Possibilities: The Difference SRV Makes" is the theme of the second international conference on Social Role Valorization, to be held June 1-4, 1999, at Boston University. Social Role Valorization, a concept that supersedes the principle of normalization, is defined as "the application of what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defense of valued social roles for people." Speakers and participants will travel from places as far as Australia, New Zealand, England, and Norway as well as from many states and provinces in North America.

The conference emphasizes the impact and practical application of Social Role Valorization in the fields of mental retardation, developmental disabilities, mental health, aging, and physical disabilities. The event offers an invitation to explore SRV fully, including the viewpoints of serious dissenters. Family members, persons with disabilities, service providers, educators, journalists, and policy makers will be represented at the event. Speakers include Wolf Wolfensberger, John O'Brien, Gunnar Dybwad, along with many other well-known figures in the disability field. It will be hosted by the North American Social Role Valorization Council.

Over 60 plenary and concurrent sessions will be held. In addition, opportunities exist for poster sessions as well as informal discussion during evening receptions.

Conference flyers are available from Jack Yates, 68 N. Main St., Carver, MA, 02330. Telephone: (508) 866-5000, Ext.347. Information can also be accessed on the SRV web page: <<http://www.SRV.21century.com.au>>.

A Summary of the Rehabilitation Act Amendments of 1998

Continued from the inside front cover

criteria applied by the Social Security Administration, to be among the most severely disabled individuals who apply for VR services. Presumed eligibility for these individuals will increase administrative efficiency, reduce costs for eligibility determinations, and speed up the delivery of employment-related services to individuals who have already been determined to have a significant disability that affects their ability to work and who require VR services.

The Amendments also streamline the IPE by eliminating unnecessary content and by requiring that the plan be amended only when substantive changes in the employment goal, services, or in service providers are made.

These steps to streamline and eliminate unnecessary administrative requirements and to speed up access to services will save states both monetary and personnel resources that can be better used to support direct services to individuals with disabilities.

Increasing High Quality Employment Outcomes. The staggering unemployment rate of individuals with disabilities, measured at nearly 70 percent by the 1998 *Louis Harris Poll*, can be reduced through efforts to assist individuals with disabilities, particularly those with the most significant disabilities, to prepare for and achieve high quality employment outcomes to which they aspire. The Act also requires that an individual's employment outcomes be consistent with that person's strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice. In this regard, the amendments address the need to increase successful employment outcomes through new provisions that emphasize telecommuting, self-employment, and small business operation as legitimate employment outcomes. Also added to the scope


of authorized services are technical assistance and other consultation services for eligible individuals who are pursuing self-employment and small business operation.

A new provision in the Act eliminates the need for an extended evaluation prior to determining that an individual with a significant disability is ineligible for VR services. The new provision replaces this requirement by instead requiring the use of trial work experiences, including on-the-job supports and/or training, before a state VR agency can determine an individual to be ineligible for services due to the severity of the individual's disability. The new trial work requirement will help ensure that individuals with significant disabilities are afforded the opportunity to engage in "real work" experiences as part of the eligibility determination process, providing a more accurate measure of whether the individual is eligible for VR services and can pursue a high quality employment outcome.

Improving Due Process. The Amendments make major changes in the former due process requirements. State VR agencies are now required to implement policies and procedures relating to mediation of disputes between individuals and the agency, in addition to providing for formal hearings before impartial hearing officers (IHO). Mediation is voluntary on the part of both parties and cannot be used by the state agency to deny or delay the right of an individual to an impartial hearing. The revised due process provisions also eliminate the review of IHO decisions by the state VR unit director. However, a state may elect to conduct impartial reviews of IHO decisions by an official from the governor's office or the head of the state VR agency if the state has both a designated state VR agency and a designated VR unit.

Linkages to State Workforce Investment Systems. For several years, Congress and the States have been attempting to reform the nation's job training system to more effectively assist a greater number of people to prepare for and obtain employment. The Workforce Investment Act (WIA) follows this theme by streamlining and consolidating several employment and training programs into a unified statewide workforce investment system. The House and Senate bills that were merged to form the WIA both reflected an awareness of the employment needs of individuals with disabilities, especially those with significant disabilities, and, like the WIA, identified the VR program as a potential key component of state workforce systems.

The Act includes numerous provisions designed to link the VR program and the workforce investment system, including common definitions, common reporting requirements on program outcomes, and requirements for cooperative agreements between VR agencies and other entities in the system. The cooperative agreements must be replicated at local levels between VR offices and local entities that carry out workforce development activities.

While the Act contains very clear expectations for coordination and cooperation between VR agencies and other entities in the workforce investment system, none of the requirements in the Act or in WIA is intended to violate the integrity of the VR program. The Committee Report that accompanied the Senate bill states unequivocally that under no circumstances will the funds of a state VR agency be diverted to any purpose other than those spelled out in the Act. Still, the required linkages between state VR agencies and other entities in the workforce investment system are intended to lead to greater training opportunities and high-quality employment outcomes for individuals with disabilities. 

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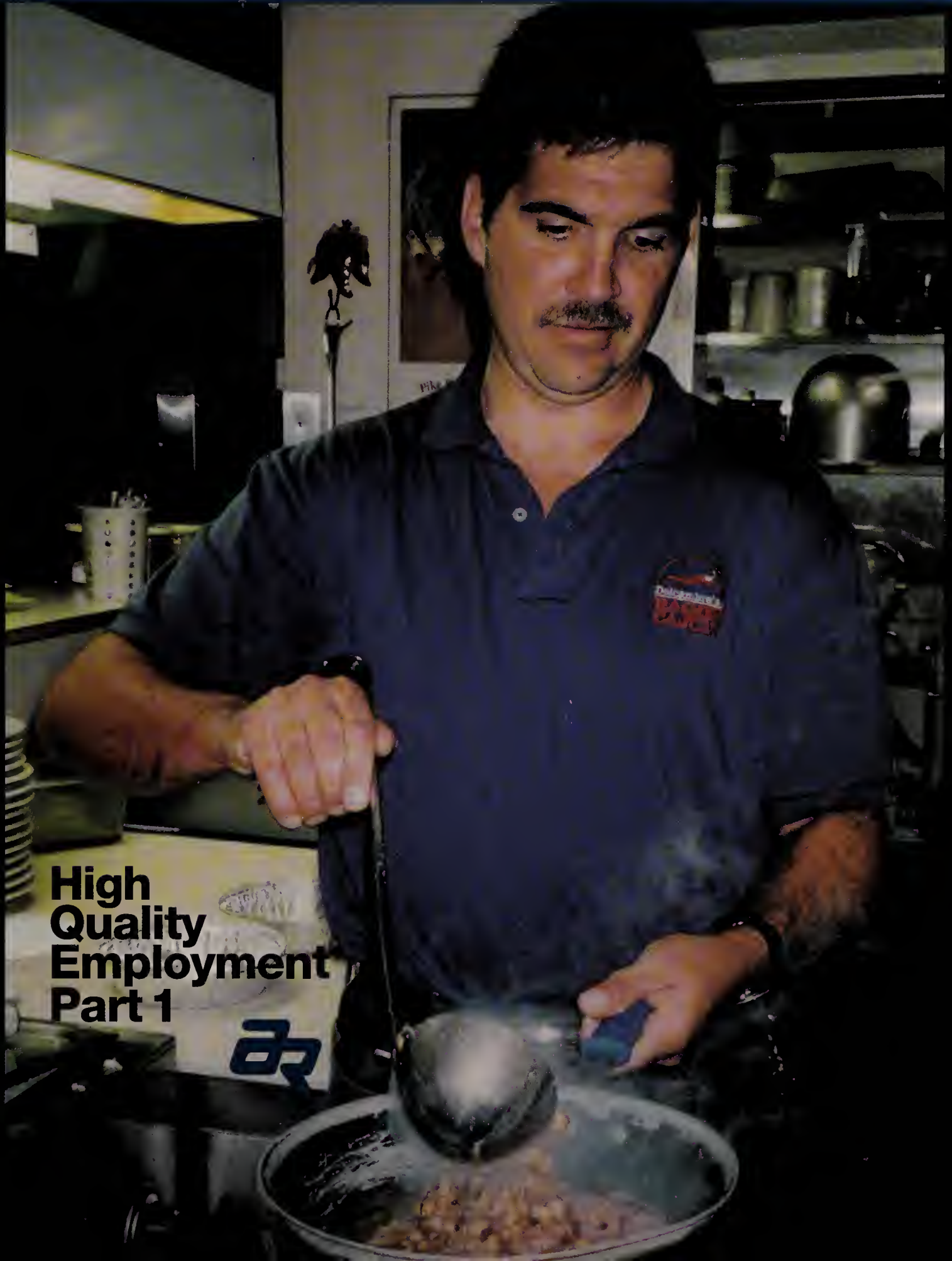
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AMERICAN REHABILITATION

WINTER
1999/2000



**High
Quality
Employment
Part 1**



High Quality Employment: What Does it Mean?



Fredric K. Schroeder
Commissioner
Rehabilitation Services Administration

When we in the vocational rehabilitation (VR) field say the phrase "high quality employment outcome," what do we mean? How do we define such an elusive and, some might say, subjective concept? How do we know when we have arrived at a point where the quality of an employment outcome is equally as important as the fact that an employment outcome has been achieved? These are the questions I have wrestled with as the Commissioner of the Rehabilitation Services Administration (RSA). RSA has tried, through various means, to address this somewhat thorny issue. Here are some of the steps we have taken and an explanation of why we took them.

Project Employ

In 1998, the President's Committee on Employment of People with Disabilities (President's Committee) approached RSA to request our assistance in producing a series of public education materials. The result was a kit designed to publicize the efforts of some VR agencies, community rehabilitation programs (CRP's) and employers to place individuals with mental retardation in "nontraditional" positions within office environments.

File clerk, data entry specialist and staffer with responsibility for destroying sensitive documents are some of the positions highlighted through "Project Employ." The positions are housed within small, medium,

and large companies which offer benefits and competitive salaries to the individuals with disabilities hired into these jobs that traditionally have not been held by those with disabilities. In fact, one of the main criteria for a job to be included as part of "Project Employ" is that the positions offer the same benefit and salary structures as that available to all employees within the company.

RSA has publicized "Project Employ" through its 1998 National Employment Conference and has issued an Informational Memorandum on the topic. It is our hope that other VR agencies will follow the lead of those states already seeking nontraditional, higher quality outcomes for individuals with mental retardation and other disabilities.

The President's Committee has copies of the "Project Employ" kit, including a videotape for use in meeting with employers, available for a nominal fee. The committee can be reached at (202) 376-6200.

Discretionary Grants

RSA's efforts to fund innovative and effective projects to improve employment outcomes are also part of our overall strategy for enhancing job quality for individuals with disabilities. Through our Projects With Industry (PWI) and Systems-Change grants, among others, we have worked to provide incentives for state VR agencies and other rehabilitation providers to seek employment opportunities for individuals with disabilities that meet or exceed our standard for quality, i.e., employment in the competitive, integrated labor market for which an individual with a disability is compensated and receives the same benefits as any other employee.

Policy Directive (PD) 97-04

PD-97-04 states its chief policy: "The employment goal for an individual with a disability receiving services under the State VR Services Program (authorized by Title I of the Rehabilitation Act) must be based, primarily, on the individual's strengths, resources, priorities, concerns, abilities, and capabilities. The employment goal also must reflect the individual's interests and informed choice to the extent that those factors are consistent with the individual's strengths, resources, priorities, concerns, abilities, and capabilities." The PD also


states that labor market conditions in the local area and the cost of providing needed services in order to achieve an outcome could not, on their face, eliminate a goal that was consistent with the strengths, resources, priorities, concerns, abilities, and capabilities of the consumer.

Using PD-97-04 as a guide, it is clear that quality employment outcomes must be determined by taking into account factors in addition to the traditional ones of wages, employment setting, and the mere fact that an employment outcome was achieved. Deference must be granted to the individual's informed choice when the desired employment outcome is consistent with the individual's strengths, resources, priorities, concerns, abilities, and capabilities.

Notice of Proposed Rulemaking on Extended Employment

A stated purpose of the Rehabilitation Act is for all "programs, projects, and activities receiving assistance under the Act [to] be carried out in a manner consistent with the principles of inclusion, integration, and full participation of the individuals" (section 2(c)(3), emphasis added). Furthermore, section 100(a)(3)(B) of the Rehabilitation Act requires the state VR services program to be carried out in a manner consistent with the principle that "[i]ndividuals with disabilities must be provided the opportunities to obtain gainful employment in integrated settings." "Extended employment," by definition, means work in a non-integrated or sheltered setting, thus making it inconsistent with both the purpose and policy of the Rehabilitation Act.

Our regulatory proposal would rescind our recognition of "extended employment" as a final employment outcome and would establish that "extended employment" will be appropriate only when used as an interim step leading to a final employment outcome in an integrated setting. We are proposing October 1, 2001, the beginning of Fiscal Year 2002, as the effective date for these amendments. This lead time will allow state agencies and others who provide VR services the opportunity to implement these changes in a manner that will be least disruptive to the beneficiaries of the state VR services program (i.e., individuals with disabilities).

In an effort to improve the overall quality of employment outcomes in the VR program, RSA has taken these and other steps. I recognize that our attempts to define "quality" do not capture each and every element that should be present; however, at its core is the idea that quality is measured by the individual and the individual's level of satisfaction with the employment outcome. We are committed to providing the best possible service to our consumers and assisting them in achieving "high quality employment outcomes. 

AMERICAN REHABILITATION

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The weakest ink is better than the strongest memory.

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Cover Photo: Danny Delcambre, owner and head chef of Delcambre's Ragin Cajun restaurant in the Pike Place Market in Seattle, prepares one of his specialties: "Red Beans and Rice with Andouille." Mr. Delcambre, who was born with Usher's syndrome and has been deaf since birth and legally blind since his teens, is also a motivational speaker for large conferences and conventions. "While in culinary school I dreamed of eventually owning my own restaurant," said Mr. Delcambre. "All the hearing students in my class got jobs cooking in fancy restaurants and hotels. No one would hire me even though I had this fabulous internship with Paul Prudhomme on my résumé. I was offered jobs washing dishes or wrapping candy bars. At that point I decided if I really wanted to cook I would have to open my own place." (Photo by Holly Delcambre)

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Postsecondary Education, Vocational Rehabilitation and Students with Disabilities: *Gaining Access to Promising Futures*

Debra Price-Ellingstad
Hugh G. Berry

Introduction

Recent estimates from the U. S. Census Bureau indicate that persons with bachelor degrees will earn approximately \$600,000 dollars more in their lifetime than those who did not receive education beyond high school. This estimate was cited by the Secretary of Education, Richard W. Riley, in his statement before Congress during the most recent reauthorization of the Higher Education Act of 1965 (Riley, 1997). Riley further noted that: "More than ever before, education is the fault line between those who will prosper in the new economy and those who will be left behind. Today's good jobs increasingly require skills and training beyond a high school education, and accessible postsecondary education is critically important to individuals as well as our Nation's economy and democracy" (p.1).

A 1998 Harris Survey asserted that Americans with disabilities are among those teetering on the edge of this fault line. Some of the survey's most troubling findings included the following:

- Only 29 percent of working-age persons with disabilities are employed full- or part-time, compared to 79 percent of the nondisabled population.
- Approximately 20 percent of adults with disabilities have not completed high school, compared to 9 percent of adults without disabilities.
- In terms of economic well-being, 34 percent of adults with disabilities live in households with total income of \$15,000 or less, compared to only 12 percent of

those without disabilities (National Organization on Disability, 1998).

If postsecondary education is indeed one of the keys to success in our rapidly changing national and global environment, then there is also some encouraging progress being made by individuals with disabilities in this regard. According to a triennial survey reported by the HEATH Resource Center, the number of college freshmen reporting some type of disability has increased substantially during the last two decades (1999). In addition, the number of postsecondary institutions offering educational opportunities for persons with disabilities has also increased to meet this greater demand (Stodden, Jessen & Lolotai, 1999). This progress may be due, in part, to a number of key pieces of legislation that are helping to improve results in the education of students and adults with disabilities. These include the Individuals with Disabilities Education Act (IDEA), initially the Education for All Handicapped Children Act of 1975 (EHA); the Rehabilitation Act of 1973, as amended; the Americans with Disabilities Act of 1990 (ADA); and the Higher Education Act of 1965, as amended (HEA).

IDEA and its predecessor statute, EHA, guarantee equality of educational opportunity for our nation's disabled students. States receiving IDEA funds must make a free appropriate public education (FAPE) available to eligible children with disabilities in mandatory age ranges. FAPE under IDEA, however, makes reference to an appropriate preschool, elementary school or secondary education in the state involved and does not make reference to postsecondary education. Further, the final IDEA regulations clar-

ify that a student who graduates from high school and is awarded a regular high school diploma is no longer entitled to FAPE. IDEA though is especially important because it helps to establish a student's preparation for entry into postsecondary education.

Prior to the enactment of IDEA more than half of America's children with disabilities were not receiving appropriate educational services. Furthermore, one million children with disabilities were excluded entirely from public education (Committee on Education and the Workforce, 1997). Since the passage of the predecessor statute to IDEA 25 years ago, significant progress has been made to improve the quality of special education and related services and to increase access to these services for our nation's disabled students. In addition, the 1997 Amendments to IDEA, while retaining and strengthening the basic protections included in the law since 1975, also have redirected the focus of the law by placing greater emphasis on effective teaching and learning strategies, raising expectations for students with disabilities, and by increasing student access to the general education curriculum. In 1990, when the EHA was renamed the IDEA, new requirements were added that a statement of needed transition services be included in each disabled student's IEP, beginning at age 16 or younger, if

Ms. Price-Ellingstad is an Education Program Specialist with the Department of Education's Office of Special Education Programs and Mr. Berry is a Policy Analyst with the Department's Office of Special Education and Rehabilitative Services.

appropriate. Transition services, which are a coordinated set of services taking into account the student's preferences and interests, are designed to facilitate movement from school to postschool activities before the student leaves the school setting. IDEA 1997 also adds new requirements for a statement of transition services needs to be included in the Individualized Education Program (IEP) of each student with a disability, beginning at age 14 or younger, if appropriate. These changes were intended, in part, to help students with disabilities appropriately prepare for and meet the academic requirements of postsecondary education settings. Since 1984, the Office of Special Education Programs, through discretionary grants under IDEA and its predecessor law, the EHA, has supported approximately 200 model demonstration projects designed to stimulate higher education possibilities for students with disabilities, including opportunities in postsecondary, vocational, technical, continuing, and adult education. Furthermore, IDEA funds have also supported HEATH, the National Clearinghouse on Postsecondary Education for Individuals with Disabilities. Also established in 1984, HEATH provides information on postsecondary educational support services, policies, procedures, and opportunities to students with disabilities and their families, higher education faculty, and support services staff.

The Rehabilitation Act of 1973, as amended, also applies to the education of disabled students. First, Section 504 of the act, which is enforced by the Department's Office for Civil Rights, prohibits discrimination against individuals with disabilities on the basis of disability by recipients of federal financial assistance, including institutions of elementary and secondary education, higher education, colleges, universities, and postsecondary vocational education and adult education programs. Title II of ADA is also enforced by the Department of Education's Office for Civil Rights, as it applies to public elementary, secondary, post-secondary, and vocational educa-

tion programs (other than schools of medicine, dentistry, nursing, and other health-related schools) and public libraries, regardless of receipt of federal funds. At the elementary and secondary level, under Section 504 and Title II, recipients that operate a public elementary or secondary education program must protect elementary and secondary education students with disabilities from discrimination on the basis of disability by providing them a free appropriate public education, as defined in the Section 504 regulation.

With respect to postsecondary education, Section 504 and Title II prohibit a broad range of discriminatory acts in areas ranging from recruitment and admissions to provision of program benefits. Section 504 and Title II require a postsecondary institution to provide auxiliary aids and services when necessary to ensure that no individual with a disability is excluded, denied services, segregated, or otherwise treated differently than other individuals. In addition, under Section 504 and Title II, students with documented disabilities may request reasonable modifications, accommodations, or auxiliary aids designed to help them participate in and benefit from their postsecondary program and activities. Auxiliary aids may include taped texts, interpreters or other effective methods of making orally delivered materials available to students with hearing impairments, notetakers, readers, videotext displays, television enlargers, talking calculators, electronic readers, Braille calculators, printers or typewriters, telephone handset amplifiers, closed captioned decoders, open and closed captioning, voice synthesizers, specialized gym equipment, other classroom equipment adapted for use by students with manual impairments, and other similar actions or services. Second, the Rehabilitation Act provides some funds, through state vocational rehabilitation (VR) agencies, to individuals determined eligible for VR services and whose individualized plan for employment specifies the need for items or services. These items or services may include assistive technol-

ogy, auxiliary aids and services, and postsecondary education tuition.

The Higher Education Act (HEA) also assists students with disabilities in a number of ways. First and foremost, the act provides financial aid, in the form of grants, loans, and work-study opportunities to qualified students, including students with disabilities, to help them pay for their postsecondary education. In addition, a series of eight outreach and support programs, collectively known as the TRIO Programs, have been established through HEA to help low income, disabled, and disadvantaged students enter and succeed in higher education. Many students with disabilities find assistance each year through TRIO programs such as Upward Bound, Student Support Services, Educational Opportunity Centers, and Talent Search.

The HEA Amendments of 1998 authorized two new programs that have much potential to improve postsecondary outcomes for students with disabilities. The first program, Gaining Early Awareness and Readiness for Undergraduate Programs (GEAR UP), provides grants to states and to partnerships between colleges and high-poverty middle schools and junior high schools to prepare students, including students with disabilities, for college. As the program name implies, GEAR UP grants target disadvantaged students early, beginning in the sixth and seventh grades, to ensure that they receive the support and preparation they will need to successfully be accepted to and graduate from postsecondary education programs. The 1998 HEA Amendments also authorized a new program of demonstration projects designed to provide faculty and administrators in postsecondary institutions with the skills and support they need to teach students with disabilities. The Office of Postsecondary Education Programs (OPE) currently funds 22 new projects through this program at universities and colleges across the country. The purpose of these projects is to develop innovative, effective, and efficient teaching methods to enhance the

skills and abilities of postsecondary faculty and administrators.

Increasing access to postsecondary education is vital for improving the employment and quality-of-life outcomes of students with disabilities. The purpose of this article is threefold: (1) to summarize and discuss current research focusing on postsecondary students with disabilities; (2) to examine emerging challenges for improving the postsecondary experiences of students with disabilities; and (3) to discuss promising practices that are helping students with disabilities to succeed in postsecondary settings.

Postsecondary Students with Disabilities--National Data

According to the 1995-1996 National Postsecondary Student Aid Study (NPSAS), roughly 6 percent of students enrolled in postsecondary education reported having some type of disability (NCES, 1999a). Of these, almost 30 percent indicated that they had a learning disability. Other disabilities reported included 23 percent with orthopedic impairments, 16 percent with hearing impairments or deafness, 16 percent with visual impairments that could not be corrected with glasses, and 3 percent with speech impairments. Twenty-one percent of the students reporting disability indicated that they had "other" health-related disabilities. Males with disabilities were more likely to enroll in postsecondary education than females, and whites with disabilities were more often represented than blacks or Hispanics. As a diverse whole, students with disabilities tended to be older and participated more often in 2-year rather than 4-year postsecondary programs (NCES, 1999a).

Students with disabilities were less likely to depend on income from parents or other family members than nondisabled students (NCES, 1999a). About half of the financially dependent undergraduates with disabilities reported receiving some type of financial aid, and this finding was not statistically different from that of students without disabilities. Both groups re-

ceived about \$6,000 in financial aid annually. Financially independent students with disabilities, however, were more likely to rely on federal aid than nondisabled students. The NPSAS findings suggest that undergraduates with disabilities rely to a greater extent on federal aid and assistance than do those without disabilities, particularly the majority of those who reported financial independence. It is important to note that the 1995-1996 NPSAS design could not account for the extent to which undergraduates received financial assistance from disability-specific federal and state programs such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI) and VR.

In terms of academic preparedness, analyses of the National Education Longitudinal Study of 1988 (NELS:98/94) showed that most high school students with disabilities were not ready for a 4-year college education. As compared to 37 percent of students without disabilities, 57 percent of students with disabilities who completed high school in 1994 were not qualified according to their performance as ranked by GPA, senior class rank, SAT/ACT scores, and aptitude testing (p. 30). Further, students with disabilities who were at least minimally qualified for a 4-year college or university program were significantly less likely to participate in these programs when compared to nondisabled students with similar academic potential. Qualified undergraduates with disabilities instead frequently veered toward 2-year postsecondary programs rather than 4-year college and university programs (p. 34). Policy implications of these findings will be discussed in a later section.

Considering the heterogeneous population of students with disabilities exiting secondary education, it should be noted that the NELS sample did not include some students with significant disabilities who were determined inappropriate for this survey. Also excluded were another 10 percent of students with disabilities who were once part of the NELS sample but later

dropped out of high school prior to graduation (NCES, 1999a). Prior research has shown that up to a third of all students receiving special education services drop out of high school (Hebbler, 1993; US Department of Education, 1994). In particular, secondary students with learning disabilities, emotional disturbances and mental retardation demonstrated particularly high dropout rates (Cameto, 1993; Newman, 1991). Of students receiving special education services, only 27 percent enrolled in postsecondary education after high school as compared to 68 percent of students without disabilities. Only 4 percent of students with disabilities had enrolled in a 4-year college. Students with disabilities who therefore stayed in high school, graduated, and were adequately prepared for a 4-year college were indeed an exceptional group.

Services and Accommodations

A *Postsecondary Education Quick Information Survey* (PEQIS) conducted between 1996 and 1998 generated important information regarding the accommodations, services, and supports provided to students with disabilities in 2- and 4-year postsecondary institutions (NCES, 1999b). In addition, PEQIS yielded data focusing on outreach activities, technology planning and collaboration between postsecondary institutions and VR agencies. This section will discuss the services and accommodations provided to students with disabilities across postsecondary institutions nationally.

In contrast to the NPSAS, the PEQIS data provided institutional enrollment estimates of students with disabilities, and these estimates varied by data collection methods. For example, some institutions based their counts on disability verification, and others on the provision of services and accommodations. All PEQIS responses, however, were contingent upon the student reporting his or her disability to the postsecondary institution rather than through an anonymous survey. And, while the NPSAS estimate of students

with disabilities in postsecondary institutions was 6 percent (NCES, 1999a), the PEQIS estimate was much smaller—only 3 percent or 428,000 students (Lewis & Farris, 1999). Still, PEQIS provided important data regarding how institutions respond to the needs of students with disabilities in postsecondary settings.

Given an array of options, PEQIS respondents were asked to identify those services, accommodations and supports that were provided to students during the academic school year. For all postsecondary institutions, 88 percent reported that alternative exam formats or additional time was provided. This accommodation was the most frequently reported among all 2- and 4-year institutions. Other commonly provided accommodations and services included tutors to assist with ongoing homework (77%); readers, classroom notetakers or scribes (69%); registration assistance or priority class registration (62%); adaptive equipment and technology (58%); textbooks on tape (55%); and sign language interpreters/transliterators (45%). In general, public 2-year and 4-year institutions were more likely to report providing these accommodations and services than comparable private institutions. Those postsecondary institutions with larger student enrollments were also more likely to report the provision of accommodations and services, and this finding was not surprising given that students with disabilities tended to enroll more often in larger colleges and universities.

The accommodations and services reported in PEQIS did not describe the extent to which students with disabilities access these services. That is, accommodations and supports were reported from an institutional perspective rather than on an individual basis. Also, while PEQIS data showed that 60 percent of postsecondary institutions reported collaborating with VR agencies, the nature and scope of coordinated activities is still unclear. The next section will focus on the interface between VR programs and postsecondary education. In particular, state VR agency

costs and consumer employment outcomes will be described, as well as services and training provided to postsecondary students who were also VR consumers.

Rehabilitation and Postsecondary Education

Using 1998 data from the 911 case-load database (RSA, 1999), Table 1 shows the numbers of VR consumers who exited the program after receiving college and university training, costs of purchased services for such training and employment outcome rates. College and university training included all academic coursework beyond high school and may cover tuition, support services and other expenses. As shown, average costs varied widely across agencies. The District of Columbia, Georgia, Maine, and Ohio agencies reported costs that averaged over \$10,000 per consumer. As groups, average college and university training costs for blind agencies and those in U.S. territories were substantially higher than others, averaging about \$14,000. On the opposite end of the spectrum, average costs for states such as California, Oregon and Texas were below \$3,000 per consumer. This variation may be influenced by a number of factors such as differing tuition costs, financial aid systems and consumer characteristics.

Employment outcome rates shown in Table 1 also vary considerably. As a group, rates in U.S. territories such as Guam, Puerto Rico, the Virgin Islands, and America Samoa were unusually high at 94.4 percent. Utah and Alabama also had relatively high employment outcome rates, 80 percent and 81 percent respectively. States such as California and Oregon, conversely, reported rates as low as 41 percent and 43 percent. The high rates reported by outlying areas may be influenced to some extent by differing reporting procedures and fewer consumers per agency. Even with these differences, the mean rate for consumers receiving college and university training was 60 percent and this was comparable to

the rate consumers who did not receive such training.

Many VR consumers receive services in addition to college and university training. For VR consumers who received college and university training, Table 2 shows the percentages of other services and training types received through the VR program. Consumers receiving college and university training also often received assessment services (87.4%). As shown by PEQIS data (Lewis & Farris, 1999), 84 percent of postsecondary institutions required some type of verification of disability for receiving disability support services and 77 percent accepted VR evaluations for eligibility purposes. Seventy-five percent of college and university VR consumers also received substantial counseling services. Other research shows that students with disabilities were more likely to receive counseling services than nondisabled students (Horn & Bertold, 1999), and VR consumers in postsecondary education appeared to receive these services at even higher rates. Maintenance (26.3%), restoration (28.7%) and other services (32.7%) were often provided. Job-finding and placement services were also frequently provided (27.5% and 21.1%), while on-the-job training was relatively rare for this population (4.5%). Notably, relatively few VR consumers (3.6%) received personal assistance services such as reader assistance, personal attendants and interpreter services.

Future Challenges

By the year 2006, the U.S. Bureau of Labor Statistics (1999) projected that 18 of the top 25 occupations with the largest and fastest employment growth, high pay and low unemployment will require at least a bachelor's degree. These occupations will consist mostly of jobs in the areas of healthcare, computer technology and education. In addition, it is anticipated that labor force groups with lower than average educational attainment will continue to experience obstacles toward obtaining jobs with higher pay. While nearly two-

Table 1
Purchased Costs and Employment Outcome
Percentages for VR Consumers Who Received
College and University Training

Agency	Number	Mean Costs of Services	Percent with Employment Outcomes
Alabama	1,076	\$6,025	81.2
Alaska	234	\$8,317	59.0
Arizona	1,204	\$5,501	44.4
Arkansas	1,287	\$4,632	74.7
California	6,088	\$2,961	41.0
Colorado	345	\$6,1065	6.8
Connecticut	356	\$8,170	61.0
Delware	96	\$7,384	46.9
District of Columbia	72	\$12,580	65.3
Florida	2,029	\$6,039	58.3
Georgia	245	\$12,568	58.0
Hawaii	125	\$4,222	51.2
Idaho	423	\$4,232	53.0
Illinois	1,483	\$7,004	52.0
Indiana	788	\$9,523	54.2
Iowa	986	\$3,440	53.7
Kansas	383	\$8,152	60.1
Kentucky	1,727	\$5,400	70.5
Louisiana	1,158	\$8,515	74.0
Maine	153	\$11,202	56.2
Maryland	487	\$7,196	67.4
Massachusetts	2,266	\$3,622	57.3
Michigan	1,624	\$4,286	45.0
Minnesota	2,285	\$2,622	47.9
Mississippi	207	\$7,144	59.9
Missouri	1,424	\$8,037	60.6
Montana	349	\$8,205	53.3
Nebraska	341	\$4,389	56.3
Nevada	262	\$3,389	49.6
New Hampshire	216	\$7,634	59.7
New Jersey	248	\$7,837	54.4
North Carolina	444	\$5,249	50.7
North Dakota	219	\$6,685	69.4
Ohio	1,408	\$10,9645	5.7
Oklahoma	1,372	\$5,406	63.3
Oregon	263	\$2,218	42.6
Pennsylvania	1,877	\$9,215	72.9
Rhode Island	77	\$8,936	62.3
South Carolina	530	\$4,712	72.6
South Dakota	189	\$6,027	70.4
Tennessee	842	\$7,386	73.2
Texas	7,580	\$2,956	54.9
Utah	1,564	\$4,786	80.0
Vermont	163	\$3,363	47.2
Virginia	592	\$5,837	62.8
Washington	1,568	\$4,377	57.5
West Virginia	553	\$5,698	70.2
Wisconsin	2,126	\$5,498	50.1
Wyoming	346	\$4,405	60.4
Territories	865	\$14,645	94.4
Blind Agencies	1,096	\$14,658	64.5
Total	53,641		60.0

thirds of future jobs will require less than an associates or bachelor's degree, these jobs provide the lowest pay and benefit options. Many of these future occupations will provide pay below the poverty threshold (CPS, 1999). Given this scenario, postsecondary education opportunities will be of vital importance for all future job seekers, particularly those with disabilities.

Postsecondary education is critically important for the development of tomorrow's work force. When controlling for sociodemographic, SSI participation, vocational rehabilitation, and other factors, Berry (1999) found that postsecondary education more than tripled the odds of achieving an employment outcome when compared to individuals with disabilities who failed to complete 12 years of education. Also, as discussed by Schmidt, Kay, Davis, and Hayward in this issue, VR consumers who earn 2- or 4-year postsecondary degrees are more likely to achieve employment outcomes and have higher earnings than consumers with less than a high school education.

Postsecondary education is key for better careers and futures among individuals with disabilities, and there are many challenges that need to be addressed in order to increase access to and success in colleges and universities. Among these challenges, interagency coordination, universal design, and transition planning for students with disabilities are particularly important for helping prepare students with disabilities to gain access to postsecondary education and employment success.

Interagency coordination. The debate between postsecondary institutions and state VR agencies regarding which party should take primary responsibility for the payment of auxiliary aids for postsecondary students who are also VR clients has been long and heated. The history of this controversy has its roots in statute, regulations and case law.

As mentioned, Section 504 of the Rehabilitation Act of 1973 requires postsecondary institutions, as recipients of federal financial assistance, to make their programs accessible to students

with disabilities. This accessibility is often accomplished through the provision of auxiliary aids and services, including interpreter services, which can be costly. In an effort to conserve limited state VR dollars, state VR agencies initially used the "comparable services and benefits provisions" of the Rehabilitation Act of 1973 to limit VR funding for the auxiliary aids needed by their clients who were students in postsecondary institutions. These provisions required state VR agencies assist their clients in locating and utilizing benefits and services from other sources comparable to those offered by VR agencies, prior to expending VR program funds.

This practice was called into question in the early 1980's by a number of court decisions and a 1981 opinion offered by the Department of Education's Office of the General Counsel (OGC). Both the judicial findings and the OGC opinion concluded that the comparable services and benefits provisions of the Rehabilitation Act of 1973 [sections 101(a)(8), 101(a)(12) and 103(a)(3)] did not categorically prohibit state VR agencies from paying for postsecondary student's auxiliary aids, if the student's individualized written rehabilitation program (IWRP) called for such auxiliary aids and postsecondary training (U.S. Department of Education, Office of Special Education and Rehabilitative Services, 1999; PEPNet, 1999). Furthermore, the OGC opinion encouraged the determination of payment responsibility between postsecondary institutions and VR agencies to be made on a case-by-case basis, with each case taking into consideration such things as the necessity of the service for the student to attain an employment objective, the VR agency's order of selection of individuals for services and the costs of such services. Thus, a wide variety of payment agreements were negotiated between state and local VR agencies and postsecondary institutions.

The passage of ADA in 1990 rekindled this debate. Some believed that the ADA had altered the status quo to place the entire responsibility for funding auxiliary aids and services on

the shoulders of postsecondary institutions. Others believed that the previous court decisions still held, and that state VR agencies should continue to share the costs associated with the provision of auxiliary aids and services for their clients.

In order to promote improved collaboration, the Rehabilitation Act of 1973 was amended in 1998 to include a compromise provision that was contained in Section 101(a)(8)(B) of the act. This provision required each state's governor, in consultation with the state VR agency and other appropriate agencies, to develop an interagency agreement or other mechanism for interagency coordination to ensure the provision of VR services to eligible individuals with disabilities. Institutions of higher education are specifically named as one of these appropriate agencies. Other named entities included Medicaid and the work force investment system. The interagency agreements must contain a provision for determining the financial responsibility of each public entity providing VR services. Simply stated, this new provision was designed to help resolve the disagreements between institutions of higher education and state VR agencies, on a state-by-state basis, concerning which agency is responsible for financing services for postsecondary students who are also VR consumers. Given this legislative context, the extent to which disagreements are minimized will ultimately result from the collaborative interactions (and compromises) between these important entities.

Universal curriculum design. The PEQIS study reported that 2- and 4-year colleges and universities are providing many individually designed accommodations, services and supports for postsecondary students with disabilities (Lewis & Farris, 1999). One area not addressed in the PEQIS, however, was the extent to which faculty at postsecondary institutions were using curriculum that incorporate universal design principles as a means to accommodate students with disabilities. This concept is relatively new to the field of postsecondary education and at

first glance the term almost seems incompatible with the individually designed accommodations that have typically been recommended for students with disabilities.

The term "universal design" refers to the design of environments and products, in this case postsecondary curricula, in such a way as to ensure that they are usable by as many people as possible, including people with disabilities. The term has its origins in architecture, where it was used most commonly to describe designs that purposefully incorporated, rather than added as an afterthought, assistive technologies and adaptations to accommodate physical access for individuals with disabilities (Orkwis & McLane, 1998). The Center for Applied Special Technology (CAST) identified three principles that are essential to universal curriculum design. These principles include the provision of multiple representations of key information to accommodate a variety of student learning preferences and needs, multiple options for students to control and demonstrate their learning and multiple options for student engagement and motivation (1998). For contact information on CAST, see the Resource List at the end of this article. The principles behind universal design have spread from architecture to areas such as product development, communications and information technologies. More recently, universal design principles have been applied to the design of elementary and secondary educational curricula.

Following the passage of the IDEA Amendments of 1997, the Office of Special Education Programs (OSEP), Office of Special Education and Rehabilitative Services (OSERS), began a concerted effort to facilitate the application of universal design principles to help students with disabilities gain full access to the general education curriculum. As a result of this effort and the work of dedicated researchers and innovative curriculum and software developers, K-12 classrooms across the country are beginning to use learning materials and activities that incor-

porate universal design principles. Examples include textbooks with built-in flexibility and software with multiple means of representation (Orkwis & McLane, 1998).

Like curb cuts and revolving doors, universally designed learning materials have the potential to benefit many diverse learners, not just learners with disabilities. Diverse learners, including those with cultural barriers and those who speak English as a second language, represent a substantial proportion of the entire learning population. As these diverse learners enter postsecondary education in greater numbers, faculty should be cognizant of universal design principles in order to better address the learning needs of all students.

This may be a more difficult task than it is in K-12 education, however, simply because postsecondary faculty have greater autonomy in selecting their textbooks and materials; and because universal curriculum design is a new concept in higher education, faculty must become knowledgeable about the benefits of using this type of curriculum with a wide variety of learners.

Beginning in October 1999, the U.S. Department of Education's Office of Postsecondary Education (OPE) funded a number of model projects designed to incorporate the principles of universal curriculum design into training and materials for postsecondary faculty to help them better accommodate the learning needs of students with disabilities. Products from these projects should be available within the next few years. For more information on these projects and other OSERS funded projects that are working on universal curriculum design, contact OPE (see the Resource List at the end of this article).

Transition planning. Since 1990, the planning and provision of transition services for students with disabilities, 16 years and older (or younger if deemed appropriate by the IEP team), has been a requirement under IDEA. Given that most high school students with disabilities are not adequately prepared for a 4-year college education, it appears that transition plan-

ning for these college-bound students may have been insufficient. Early and effective transition planning for all students with disabilities can help them prepare adequately to enter and succeed in postsecondary education if this is their choice.

A number of new provisions contained in the IDEA Amendments of 1997 helps to support this type of transition planning. For example, IDEA now requires that beginning at age 14, or earlier if appropriate, a student's IEP must include a statement of the student's transition services needs that focus specifically on the student's courses of study. The purpose of this provision is to help students and their families, in collaboration with school personnel, begin planning earlier for their high school course work (such as participation in advanced-placement courses or a vocational education program). This early planning should help to ensure that students with disabilities wishing to attend postsecondary education have all of the prerequisite academic course work needed for admission to the college or university of their choice.

Other new provisions of the IDEA amendments, while not specifically tied to transition planning are also important for students with disabilities considering education beyond high school. These provisions place increased emphasis on student involvement and progress in the general education curriculum and they require regular education teacher participation in the development, review and revisions of IEPs. Additional new IDEA provisions require students with disabilities to participate in state and district-wide assessments of achievement. Each of these new provisions may help students with disabilities to better prepare for the complexity and rigor of postsecondary education.

Although these new IDEA provisions should help to improve student transitions from secondary to postsecondary education, a recent study of the implementation of IDEA transition requirements provides evidence for concern (Johnson, Sharpe, Sinclair, Hasazi, &

Furney, 1997). One major area of concern identified in this study was the lack of meaningful student involvement in transition planning. For example, few schools in this study reported using promising practices, such as student-centered planning or student-led IEP meetings, to facilitate student involvement in transition planning (Ibid, 1997). This type of involvement, although important for all students with disabilities, is particularly important for students planning to attend postsecondary education. Once on campus, students with disabilities typically need to advocate for their own services and accommodations. Thus, high schools should take advantage of every opportunity to promote the self-determination of college-bound students with disabilities. One such opportunity can be found in good transition planning.

When a student is accepted to a postsecondary institution, he or she may find it helpful to include in the transition planning someone from that institution's services for students with disabilities and/or financial aid office. This is important because many colleges and universities require documentation of a disability in order to provide services and accommodations to students with disabilities. Good transition planning in high school should help students and their families acquire the up-to-date assessments that are required to receive such services after admission. Moreover, effective transition planning will help college-bound students with disabilities and their families in considering the financial implications of higher education, including tuition and living costs, financial aid, scholarships, and work-study opportunities. And as mentioned earlier, the recent amendments to the Rehabilitation Act of 1973 will require education and VR agencies to collaborate in order to improve postschool options, including financial assistance opportunities.


Conclusion

Postsecondary education is vital for the employment success of students with disabilities. Along with others,

Table 2
Additional Purchased Costs and Employment Outcome Percentages for
VR Consumers Who Received College and University Training

Service and Training Type	Description	Percent
Assessment Services	Included diagnosis and evaluation to determine applicant eligibility for VR services and/or to determine the nature and scope of services to be provided.	87.4
Counseling Services	Counseling and guidance provided to the individual only to a substantial degree (i.e., counseling was of overriding importance in the totality of rehabilitation services delivered as determined by the substantial level of such services provided).	75.4
Transportation Services	Included any service (e.g., vans, taxi cabs, private cars) provided or arranged for by the state VR agency to enable the individual to arrive at appointments for assessment, medical services, training, or any other rehabilitation service, as well as to permit the individual to get to work.	41.4
Other Services	Services that cannot be categorized in any other classification (i.e., occupational tools and equipment, initial stocks and licenses and services to family members to benefit the individual).	32.7
Restoration Services	Included services such as surgery, therapy, treatment and hospitalization needed to correct or substantially modify a physical or mental condition.	28.7
Job-Finding Services	Services that included providing sufficient information to the individual to permit or arrange for a job interview with a potential employer.	27.5
Maintenance	Services Included services provided to cover the additional costs incurred by the individual while he or she is undergoing rehabilitation.	26.3
Job Placement	Services Services rendered when the individual is referred to and hired by an employer. Does not include situations when the individual found a job on his or her own without training or support. Also, persons who are already employed at the time of application are not included.	21.1
Miscellaneous Training	Included services provided to cover the additional costs incurred by the individual while he or she is undergoing rehabilitation.	18.6
Adjustment Training	Training designed to help the individual adjust to a particular situation hindering his or her disability (e.g., work conditioning, mobility training, literacy training, lip reading, braille)	17.1
Business/Vocational Training	Included training in business/commercial schools or colleges and vocational trade schools.	16.5
Assistive Technology Services	Services that directly assist an individual in the selection, acquisition or use of assistive technology device (i.e., evaluation, customizing or repairing assistive technology devices, coordination with other therapies and services, and training and technical assistance for the consumer and his or her family as appropriate).	11.3
Assistive Technology Devices	Devices that enable the individual to receive rehabilitation services, improve his or her personal status or make it possible for the person to work or become more productive.	9.6
On-the-Job Training	Training by a prospective employer in which the individual usually works for wages while learning job skills.	4.9
Personal Assistance Services	A range of services designed to assist an individual perform daily living activities on or off the job that the individual would typically perform if he or she did not have a disability. Such services are designed to increase the individual's control in life and ability to perform everyday activities. Personal assistance may include reader, interpreter and other types of services.	3.6
Rehabilitation Engineering Services	Included a complex set of services entailing an original design or concept intended to help the individual function personally, socially and/or vocationally. These services may incorporate the innovative use of devices, equipment, aids, environmental modifications, and transportation and would typically require the use of a rehabilitation technology specialist.	2.8

Source: Rehabilitation Services Administration. (1995). Reporting manual for the RSA 911 case service report. Washington, DC: Author

the future challenges described here will require effective policies and practices between postsecondary institutions and VR agencies. In addition, disability support service providers, faculty, rehabilitation professionals, students, and families—all have key roles in promoting successful postsecondary experiences and outcomes. Future research should focus on the relative effectiveness of postsecondary accommodations and supports, factors that are positively associated with postsecondary retention and degree attainment for VR consumers and the extent to which postsecondary institutions, VR agencies and individuals share responsibility for the costs of educating this important population. 

Resource List

HEATH Resource Center
National Clearinghouse on
Postsecondary Education for
Students with Disabilities
American Council on Education
One Dupont Circle, Suite 800
Washington, DC 20036
Voice and TTY: (800) 544-3282
Voice/TTY: (202) 939-9320
Fax: (202) 833-4760
URL: <http://www.acenet.edu/about/programs/access&equity/heath/home.html>

National Center for the Study of
Postsecondary Education Supports
Rehabilitation Research and
Training Center (RRTC)
University of Hawaii Center on
Disability Studies
1776 University Avenue UA4-6
Honolulu, HI 96822
Voice: (808) 956-5011
Fax: (808) 956-5713
URL: <http://www.rrtc.hawaii.edu>

CAST (Center for Applied
Special Technology)
39 Cross Street, Suite 201
Peabody, MA 01960
Voice: (987) 531-8555
TTY: (987) 538-3110
Fax: (987) 531-0192
URL: <http://www.cast.org>

Demonstration Projects to Ensure
Students with Disabilities Receive a
Quality Higher Education
Office of Postsecondary Education
(OPE)
U.S. Department of Education
Washington, D.C. 20202
Voice: (202) 502-7647
TTY: (202) 205-9277
URL: <http://www.ed.gov/offices/OPE/disabilities>

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Basic Skills and Labor Market Success: Findings from the VR Longitudinal Study

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As noted in recent research on education and labor force participation, completion of a postsecondary degree is a major contributor to a person's subsequent success in the labor market (Boesel, 1998; Grubb, 1998). Access to postsecondary education and to the accommodations that can facilitate completion of a course of study has historically been problematic for youth with disabilities (Price-Ellingstad & Berry, 2000); this lack of access can limit the career prospects of individuals with disabilities. Our current research indicates that educational deficits at other levels can also have seriously deleterious effects on the employment and earnings experiences of individuals with disabilities. This research addresses the question: To what extent do deficits in basic skills limit employment or earnings potential among individuals with disabilities and what interventions can vocational rehabilitation (VR) agencies use to ameliorate these deficits?

In this article, we examine data from the *Longitudinal Study of the Vocational Rehabilitation Services Program*, sponsored by the Rehabilitation Services Administration (RSA) of the U.S. Department of Education's Office of Special Education and Rehabilitative Services. These data indicate that deficits in basic skills are a major deterrent to VR consumers' ability to earn living wages even when they succeed in entering competitive employment as a result of VR services. These findings lead to our recommendation that the state-federal VR program, with support from RSA,

explores strategies for improving the mastery of basic skills among consumers in need of such assistance. We suggest that services to improve basic skills can facilitate entry into further education and training and subsequently lead to improved employment and earnings among a significant subset of individuals who enter VR services.

Overview of the VR Longitudinal Study

Commissioned by RSA and mandated by the Congress in the 1992 Rehabilitation Act Amendments, the *Longitudinal Study of the Vocational Rehabilitation Services Program* is a national impact evaluation that investigates the effects of VR services on economic and other outcomes for individuals with disabilities who receive such services. The study's design, reflecting the typical service patterns of VR program participants, called for repeated contacts with individuals over a 3-year period to obtain comprehensive information to support judgments about the benefits the VR system provides to consumers and society. The findings contained in this article come from two primary sources. The first is information abstracted from VR case files of study participants, including reading and mathematics achievement levels where reported. The second is a series of detailed interviews administered to all study participants at the time of entry into the study and at annual intervals for a subsequent 3-year period. These interviews obtain information on work history, functional status, vocational interests, attitudinal characteristics, perspectives on the VR experience, retention of earnings and employment, and other outcomes, such

as independence and community integration, over time.

The longitudinal study drew a nationally representative sample of over 8,000 respondents, including applicants for VR services (some of whom were not accepted for services) and current and former VR consumers. Weighted, this sample represents 1,001,870 people with disabilities who applied for or received VR services. Data collection began in November 1994 and concluded in January 2000.

Data from this study provide insight into the relationship between educational experiences and employment outcomes. In this article, we consider the characteristics and experiences, including educational experiences, of VR consumers who achieved a competitive employment outcome at exit from VR. We are particularly interested in predicting whether the earnings levels of these persons are sufficient to enable them to achieve financial independence, as well as the interventions that may improve the likelihood of earning a living wage. Here, we define earnings greater than \$9.00 per hour as a living wage.

To examine this issue, we first describe the educational status of VR consumers at entry to VR along dimensions of demographic and disability

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characteristics. We then examine relationships between these characteristics and earnings of consumers who obtain competitive employment as a result of VR services, as well as relationships among earnings, educational characteristics, measures of functional status, and attitudes (e.g., self-esteem, internal) that may affect employment success. Finally, we report findings on the relative contribution of educational status and receipt of educational services from VR to the earnings levels that consumers achieve as a result of VR.

Study Findings

We conducted three sets of analyses. In the first analysis, we examined demographic characteristics and type and significance of disability by educational status measures (grade level achievement in reading, grade level achievement in math, and number of years of education consumers have completed when they enter VR) and average earnings; results from these analyses appear in Tables 1 and 2. Next, we looked

at the relationship of demographic, disability, attitudinal, and educational factors to hourly earnings. For this analysis, we categorized hourly earnings into four levels — up to \$5.00, between \$5.01 and \$7.00, between \$7.01 and \$9.00, and greater than \$9.00. We focus on differences between individuals who earn very low earnings (up to \$5.00 per hour) and those who earn a living wage (greater than \$9.00 per hour). Tables 3 through 6 present these results. Finally, to explore further important differences revealed in these tables, we present a correlational analysis of selected factors and then a regression analysis that predicts earnings levels from educational characteristics.

Overall, 78.4 percent of VR consumers who left VR with an employment outcome entered competitive employment. Table 1 shows the average years of education, reading and math achievement levels and earnings at closure by demographic characteristics. Table 2 contains average years of education, reading and math achievement

levels and earnings at closure by type and significance of disability.

As shown in Table 1, competitively employed consumers overall average 12.1 years of education, a grade level reading achievement of 8.5, a grade level math achievement of 7.8, and hourly wages of \$7.56 (median of \$6.25). While men have lower basic skills achievement levels than women (8.1 versus 8.9 for reading, 7.6 versus 8.0 for math), they earn substantially higher wages (\$7.91, with a median of \$6.50, for men, versus \$7.18, with a median of \$6.00, for women). On average, white consumers earn higher than average hourly wages (\$7.73; median of \$6.45), while minority consumers earn lower than average (\$6.65; median of \$5.96). Additionally, minority consumers average fewer years of education (11.7 versus 12.2) and lower grade level achievement in reading and math (7.0 versus 8.8 for reading achievement, 6.6 versus 8.1 for math achievement) than white consumers.

Earnings, years of education and achievement levels are all higher at

Table 1
Characteristics of Competitively Employed Consumers by Gender, Race, Age, and Receipt of Public Benefits at Entry

Characteristic	Percentage of competitively employed consumers	Grade Level in Reading Achievement	Grade Level in Math Achievement	Years of Education	Earnings at Closure
Percentage competitively employed of all consumers	78.4%				
Gender		<i>Mean (Median)</i>	<i>Mean (Median)</i>	<i>Mean (Median)</i>	<i>Mean (Median)</i>
Male	52.8%	8.1 (8.0)	7.6 (7.0)	12.0 (12.0)	\$7.91 (\$6.50)
Female	47.2%	8.9 (10.0)	8.0 (7.2)	12.2 (12.0)	\$7.18 (\$6.00)
Race/ethnicity					
White	85.2%	8.8 (9.7)	8.1 (7.5)	12.2 (12.0)	\$7.73 (\$6.45)
Minority	14.8%	7.0 (7.0)	6.6 (6.0)	11.7 (12.0)	\$6.65 (\$5.96)
Age					
<=25	14.5%	6.0 (5.1)	5.4 (5.2)	11.1 (11.0)	\$5.97 (\$5.25)
26-35	25.5%	8.4 (9.0)	7.8 (7.0)	12.1 (12.0)	\$7.09 (\$6.00)
36-45	29.6%	9.3 (11.0)	8.5 (8.0)	12.4 (12.0)	\$7.82 (\$7.00)
46-55	20.5%	10.6 (12.0)	9.7 (10.0)	12.5 (12.0)	\$8.64 (\$7.00)
>55	9.8%	9.2 (10.0)	8.5 (8.0)	11.7 (12.0)	\$8.09 (\$6.49)
Receipt of public benefits at entry					
Yes	28.8%	8.2 (8.0)	7.4 (7.0)	12.2 (12.0)	\$6.94 (\$5.98)
No	71.2%	8.6 (9.0)	8.0 (7.6)	12.1 (12.0)	\$7.82 (\$6.50)
All competitively employed consumers	100.0%	8.5 (9.0)	7.8 (7.0)	12.1 (12.0)	\$7.56 (\$6.25)

Source: VR Longitudinal Study, November 1999

Table 2
Characteristics of Competitively Employed Consumers by
Type, Significance and Onset of Disability

Characteristic	Percentage of competitively employed consumers	Grade Level in Reading Achievement	Grade Level in Math Achievement	Years of Education	Earnings at Closure
Percentage competitively employed of all consumers	78.4%				
Type of disability		<i>Mean (Median)</i>	<i>Mean (Median)</i>	<i>Mean (Median)</i>	<i>Mean (Median)</i>
Mental illness	18.0%	9.8 (11.5)	8.6 (8.8)	12.4 (12.0)	\$7.33 (\$6.24)
Mental retardation	7.4%	3.9 (3.0)	4.0 (3.0)	11.1 (12.0)	\$5.03 (\$4.96)
Learning disability	8.5%	6.5 (5.7)	6.1 (6.0)	11.3 (12.0)	\$6.52 (\$5.98)
Sensory disability	16.7%	8.7 (9.0)	8.5 (8.0)	12.2 (12.0)	\$8.93 (\$7.20)
Physical disability	40.2%	10.0 (12.0)	9.1 (9.0)	12.2 (12.0)	\$7.76 (\$6.51)
Other	9.1%	9.5 (10.0)	8.3 (8.0)	12.1 (12.0)	\$7.68 (\$6.40)
Significance of disability					
Significant/most significant	77.0%	8.4 (8.7)	7.7 (7.0)	12.2 (12.0)	\$7.49 (\$6.24)
Not significant	23.0%	8.8 (10.0)	8.2 (8.0)	11.7 (12.0)	\$7.83 (\$6.50)
Onset of disability					
Congenital	29.5%	6.3 (5.1)	5.9 (5.6)	11.8 (12.0)	\$6.67 (\$5.50)
Acquired	70.5%	10.0 (12.0)	9.0 (9.0)	12.3 (12.0)	\$8.00 (\$6.60)
All competitively employed consumers	100.0%	8.5 (9.0)	7.8 (7.0)	12.1 (12.0)	\$7.56 (\$6.25)

Source: VR Longitudinal Study, November 1999

higher age ranges through age 55, at which point they decrease slightly. For example, competitively employed consumers 25 years or younger earn an average \$5.97 (median of \$5.25) per hour compared to \$8.64 (median of \$7.00) per hour for those 46 to 55 years old and \$8.09 (median of \$6.49) for consumers over 55. The youngest consumers average 11.1 years of education, a grade level reading achievement of 6.0 years and a math achievement level of 5.4 years, while those aged 46 to 55 have a mean of 12.5 years of education, a mean reading achievement level of 10.6 and a mean math achievement level of 9.7. Individuals over 55 average 11.7 years of education, a grade level achievement in reading of 9.2 and a math achievement level of 8.5.

Individuals who received public benefits (including SSI, SSDI, AFDC, veterans' benefits, and other disability benefits) average lower reading and math achievement grade levels (8.2 versus 8.6 for reading, 7.4 versus 8.0 for math) than other individuals, although their average years of education are very similar (12.2 versus 12.1). Additionally,

these individuals earn much lower wages (\$6.94, with a median of \$5.98, versus \$7.82, with a median of \$6.50).

As Table 2 indicates, individuals with physical disabilities form the largest group of competitively employed consumers with disabilities (40.2%); they also earn higher hourly wages than average (\$7.76, with a median of \$6.51, versus \$7.56, with a median of \$6.25) and have slightly more education (12.2) and higher grade levels of reading and math achievement (10.0 for reading achievement, 9.1 for math achievement) than the average (12.1 years of education; 8.5 for reading achievement, 7.8 for math). Those with mental retardation, on the other hand, constitute only 7.4 percent of competitively employed consumers, earn substantially less per hour (\$5.03; median of \$4.96), are less well educated (mean of 11.1 years), and have very low reading and math grade level achievement (3.9 for reading achievement, 4.0 for math achievement). Consumers with learning disabilities (8.5% of competitively employed consumers) also earn lower than average hourly wages (\$6.52; median of \$5.98), have

fewer years of education (11.3), and have lower reading and math achievement levels (6.5 for reading, 6.1 for math). Consumers with significant or most significant disabilities (77.0% of all consumers) have lower earnings than do persons with nonsignificant disabilities (\$7.49, with a median of \$6.24, versus \$7.83, with a median of \$6.50), as well as lower reading and math achievement (8.4 versus 8.8 for reading, 7.7 versus 8.2 for math); however, they average more years of education (12.2 versus 11.7). Consumers with congenital disabilities have lower reading and math achievement (6.3 versus 10.0 for reading, 5.9 versus 9.0 for math) fewer years of education (11.8 versus 12.3), and lower wages (\$6.67, with a median of \$5.50, versus \$8.00, with a median of \$6.60) than do those with acquired disabilities.

To look more closely at factors that influence earnings levels, we analyzed demographic, disability, attitudinal, and educational characteristics by earnings levels. These results appear in Tables 3 through 6. We conducted significance tests¹ to detect differences on

these factors between individuals earning no more than \$5.00 per hour and those earning more than \$9.00 per hour.

Table 3 reports differences in earnings levels at VR closure by consumers' demographic characteristics. While we found no significant difference between the percentage of men earning low, versus high, wages (25.8% versus 26.2%), women are almost twice as likely to be in the low wage group as in the high wage group (32.6% versus 17.2%). On average, earnings increase as consumers age; the mean age for those earning \$5.00 or less per hour was 37.5, while the mean age for consumers earning more than \$9.00 per hour was 43.0. Race also has a significant relationship to earnings levels: African-Americans and Hispanics are more than three times as likely to earn low wages as high wages (34.3 versus 9.3% for African-Americans; 36.3 versus 9.9% for Hispanics), while Asians are almost four times as likely to earn high wages as low wages (39.8% versus 10.5%). Finally, those who received public benefits at entry to VR (including SSI, SSDI, AFDC, veteran's benefits, and other

disability benefits) were twice as likely to earn low wages as high wages (35.4% versus 17.5%).

As Table 4 shows, disability characteristics also affect earnings levels. Individuals with mental illness, learning disabilities and mental retardation are more likely to earn low wages than high wages (30.3% versus 18.5% for those with mental illness; 33.2% versus 11.9% for those with learning disabilities; 64.0% versus 1.4% for those with mental retardation—the largest difference of all). Additionally, consumers with significant or most significant disabilities and those with congenital disabilities are more likely to earn low wages than high wages (30.0% versus 20.6% for consumers with significant or most significant disabilities; 37.5% versus 14.7% for consumers with congenital disabilities). Although there were no significant differences in gross motor functioning or in personal care functioning between these two groups, those earning high wages scored significantly higher on the cognitive functioning scale than did those earning low wages (1.93 versus 1.83).

Consumers' self-esteem and locus of control at entry are also strongly related to earnings levels at closure for VR consumers who entered competitive employment (Table 5). Those with high earnings have significantly higher self-esteem scores at entry to VR (2.64 versus 2.46) and are less likely to believe that chance or other people determine their experiences and outcomes (1.51 versus 1.75 for chance; 1.52 versus 1.76 for powerful others). The two groups did not differ significantly in terms of internality, although those in the high wage category were somewhat higher on this dimension (2.55 versus 2.49 for those in the low wage category).

Table 6 reports our analyses of the relationship between educational characteristics at entry to VR and earnings levels at closure for persons who entered competitive employment. As shown, consumers who are in school at entry to VR are slightly more likely to earn the lowest hourly wage rather than the highest (32.9% versus 21.5%). However, consumers who received special education services in high school are more than seven times more

Table 3
Demographic Characteristics by Earnings Levels

Characteristic	EARNINGS LEVELS				Total
	Less than or equal to \$5 per hour	\$5.01–\$7.00 per hour	7.01–\$9.00 per hour	Greater than \$9.00 per hour	
Percentage competitively employed of all consumers	29.0%	31.9%	17.2%	21.9%	100.0%
Gender	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>
Male	25.8%	30.9%	17.1%	26.2%	100.0%
Female*	32.6%	33.0%	17.3%	17.2%	100.0%
Total*	29.0%	31.9%	17.2%	21.9%	100.0%
Age*	<i>Mean (median)</i>	<i>Mean (median)</i>	<i>Mean (median)</i>	<i>Mean (median)</i>	<i>Mean (median)</i>
Range	37.5 (36.0)	38.0 (37.0)	41.0 (40.0)	43.0 (42.0)	39.4 (39.0)
	18–91	18–86	20–77	19–78	18–91
Race/ethnicity	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>
White	28.4%	30.3%	17.6%	23.7%	100.0%
African-American*	34.3%	41.5%	15.0%	9.3%	100.0%
Alaska Native or American Indian	27.9%	40.4%	13.1%	18.6%	100.0%
Asian or Pacific Islander*	10.5%	30.6%	19.2%	39.8%	100.0%
Total*	28.9%	31.8%	17.3%	22.0%	100.0%
Of Hispanic origin*	36.3%	37.2%	16.7%	9.9%	100.0%
Receipt of public benefits at entry*	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>
	35.4%	30.0%	17.1%	17.5%	100.0%

* Indicates a significant difference in means or percentages between those earning less than or equal to \$5.00 per hour and those earning more than \$9.00 per hour ($p < .05$).

Source: VR Longitudinal Study, November 1999

Table 4
Disability Characteristics by Earnings Levels

EARNINGS LEVELS

Characteristic	Less than \$5 per hour	\$5.00–\$7.00 per hour	7.00–\$9.00 per hour	Greater than \$9.00 per hour	Total
Type of disability	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>
Mental illness*	30.3%	31.8%	19.4%	18.5%	100.0%
Mental retardation*	64.0%	32.9%	1.7%	1.4%	100.0%
Learning disability*	33.2%	43.0%	11.9%	11.9%	100.0%
Sensory disability	19.7%	28.7%	21.3%	30.2%	100.0%
Physical disability	25.8%	30.1%	18.6%	25.6%	100.0%
Other	24.5%	35.4%	17.0%	23.1%	100.0%
Total	29.0%	31.9%	17.2%	21.9%	100.0%
Significance of disability	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>
Significant/most significant*	30.0%	31.9%	17.6%	20.6%	100.0%
Nonsignificant	25.9%	31.7%	16.1%	26.4%	100.0%
Total*	29.0%	31.8%	17.2%	21.9%	100.0%
Onset of disability	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>
Congenital*	37.5%	35.2%	12.6%	14.7%	100.0%
Acquired	25.2%	29.9%	19.3%	25.6%	100.0%
Total*	28.9%	31.5%	17.3%	22.3%	100.0%
Functional limitations at entry**	<i>Mean</i>	<i>Mean</i>	<i>Mean</i>	<i>Mean</i>	<i>Mean</i>
Gross motor function	1.88	1.86	1.86	1.87	1.87
Cognitive function*	1.83	1.89	1.93	1.93	1.89
Personal care function	1.98	1.99	1.98	1.98	1.98

* Indicates a significant difference in means or percentages between those earning less than or equal to \$5.00 per hour and those earning more than \$9.00 per hour ($p < .05$).

** Based on the results of a factor analysis, we created these three composite scales of functional status from ADL and IADL questions. Each scale ranges from 1 to 2, with a higher score indicating higher levels of functioning, and all three scales have acceptable levels of reliability (alpha greater than .80).

Source: VR Longitudinal Study, November 1999

Table 5
Attitudinal Characteristics at Entry by Earnings Levels at Closure**

EARNINGS LEVELS

Characteristic	Less than or equal to \$5 per hour	\$5.01–\$7.00 per hour	7.01–\$9.00 per hour	Greater than \$9.00 per hour	Total
	<i>Mean</i>	<i>Mean</i>	<i>Mean</i>	<i>Mean</i>	<i>Mean</i>
Self-esteem*	2.46	2.51	2.54	2.64	2.53
Locus of control:					
Chance*	1.75	1.72	1.63	1.51	1.67
Powerful others*	1.76	1.70	1.64	1.52	1.66
Internality	2.49	2.49	2.51	2.55	2.51

* Indicates a significant difference in means or percentages between those earning less than or equal to \$5.00 per hour and those earning more than \$9.00 per hour ($p < .05$).

** Based on the results of a factor analysis, we created a self-esteem scale and three locus of control scales from items on psychosocial functioning. Each scale ranges from 1 to 3, and all scales have acceptable levels of reliability (alpha greater than .80). Items were coded so that a higher score indicates more of the given characteristic. The chance scale measures the extent to which a person believes that chance has an important effect on his/her experiences and outcomes; the powerful others scale measures the extent to which a person believes that other people have a major influence on his/her experiences and outcomes, and the internality scale measures the extent to which a person believes that he/she has control over his/her own life.

Source: VR Longitudinal Study, November 1999

Table 6
Educational Characteristics by Earnings Levels

EARNINGS LEVELS

Characteristic	Less than or equal to \$5 per hour	\$5.01–\$7.00 per hour	7.01–\$9.00 per hour	Greater than \$9.00 per hour	Total
	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>
Still in school	32.9%	31.0%	14.7%	21.5%	100.0%
Received special education services*	49.4%	33.1%	11.1%	6.4%	100.0%
	<i>Mean (median)</i>	<i>Mean (median)</i>	<i>Mean (median)</i>	<i>Mean (median)</i>	<i>Mean (median)</i>
Years of education completed*	11.4 (12.0)	11.9 (12.0)	12.3 (12.0)	13.1 (12.0)	12.1 (12.0)
Reading achievement level*	7.1 (6.0)	8.4 (9.0)	9.9 (11.0)	10.3 (12.0)	8.5 (9.0)
Mathematics achievement level*	6.4 (6.0)	7.6 (7.0)	9.0 (8.8)	9.9 (10.0)	7.8 (7.0)
	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>	<i>Percentage</i>
Receipt of postsecondary education service through VR*	16.0%	31.9%	21.2%	30.8%	100.0%
Receipt of postsecondary education degree (of those who received a service)*	14.4%	24.7%	24.1%	36.8%	100.0%

* Indicates a significant difference in means or percentages between those earning less than or equal to \$5.00 per hour and those earning more than \$9.00 per hour ($p < .05$).

Source: VR Longitudinal Study, November 1999

likely to earn the lowest wages than the highest hourly wages (49.4 percent versus 6.4 percent). (We note that 31.0 percent of these consumers have mental retardation as their primary disability. As reported in Table 2, consumers with mental retardation have lower post-VR earnings than persons with other disabilities.) Furthermore, on average, persons who earn more than \$9.00 per hour have almost 2 more years of education than those who earn \$5.00 or less per hour (13.1 versus 11.4), and they average more than three grade levels higher in reading and math achievement (10.3 versus 7.1 for reading achievement, 9.9 versus 6.4 for math achievement). Again, higher achievement in basic skills is associated with higher earnings for the jobs that consumers obtain as a result of VR services.

Individuals with low earnings levels also have low grade level achievement scores. As consumers' basic skills increase, their earnings also increase. Average reading achievement is over one grade level higher for the group earning between \$5.01 and \$7.00 per hour (8.4) than for the group earning up to \$5.00 per hour (7.1); while the group earning between \$7.01 and \$9.00 per hour has even higher reading achieve-

ment levels (from 8.4 to 9.9). On average, individuals earning over \$9.00 per hour have somewhat higher reading achievement levels than those earning between \$7.01 and \$9.00 per hour (10.3 versus 9.9). Increases in math achievement levels follow a similar pattern, with a large jump between the first two wage groups (from 6.4 to 7.6), an even more substantial increase between the second and third groups (7.6 to 9.0), and a more modest increase between the third wage group and the highest wage group (9.0 to 9.9). As these findings demonstrate, the relationship between basic skills achievement and wages is strong at all earnings levels.

While it seems clear that the demographic, disability, attitudinal, and educational characteristics of consumers at entry to VR have a substantial influence on their earnings potential, we also examined selected VR experiences to assess the extent to which the services that VR consumers obtain have an effect on their subsequent earnings. Very few VR consumers (less than one percent) received basic literacy instruction while in VR, so we were unable to analyze the effects of such services on consumers' subsequent earnings. We looked specifically at the

effects of receipt of postsecondary education services and of the receipt of a postsecondary education degree through VR. As other research has shown (Price-Ellingstad and Berry, 2000), postsecondary education positively affects earnings levels. Table 6 reports our findings on postsecondary education services. These services include enrollment in business or vocational-technical school, a 2-year community college, or a 4-year college or university. As shown, individuals who received any postsecondary education service through a VR agency (32.6% of consumers) were almost twice as likely to earn the highest wages than the lowest wages (30.8% versus 16.0%), and those who also completed a postsecondary degree (11.8% of consumers) were even more likely to earn the highest rather than the lowest wages (36.8% versus 14.4%).

Since these analyses revealed significant differences among individuals who earned low wages versus those who earned high wages, we decided to explore these differences further by computing the correlation coefficients between earnings and variables that we hypothesized were related to earnings. Each correlation coefficient de-

scribes the direction and magnitude of the linear relationship between two variables. If the coefficient is positive, individuals with a high value for one variable are likely to have a high value for the other variable. If the coefficient is negative, individuals with a high value for one variable are likely to have a low value for the other variable. The absolute value of the coefficient represents the magnitude of this relationship; pairs of variables with correlations close to 1 or -1 are more strongly related to each other than those with values close to zero.

Table 7 shows the correlation coefficients between earnings and years of education, reading and math achievement, receipt of postsecondary service, receipt of postsecondary degree, functional status measures, self-esteem, and three locus of control scales.² Reading and math achievement levels are more highly correlated with earnings (.29 for reading achievement and .34 for math achievement) than are years of education (.17); receiving special education services in high school is associated with lower earnings (-.25). Both receipt

of postsecondary service and receipt of postsecondary degree have significant, but small, correlations with earnings (.08 for postsecondary service, .06 for postsecondary degree). All of the educational characteristics at entry to VR relate more strongly to earnings at closure than do the functional status measures (.08 for cognitive function, nonsignificant correlations for gross motor function and personal care function) or the attitudinal measures (.07 for self-esteem, -.06 for chance, -.07 for powerful others and a nonsignificant correlation for internality). As these correlation coefficients demonstrate, educational characteristics have the strongest relationship to earnings among the variables we examined. Therefore, we decided to look at the relative contribution of these variables to earnings.

With the correlational analysis, it is not clear whether the effect of postsecondary services results from the services themselves or from an interaction between the educational characteristics at VR entry and receipt of these postsecondary services from VR. Therefore,

we chose to look at the effects of receipt of any postsecondary service through VR and the subsequent attainment of a postsecondary degree after taking into account the educational characteristics that VR consumers bring to VR. To examine this issue, we conducted a multiple regression analysis to predict earnings at closure³ from educational characteristics, including receipt of special education services in high school, number of years of education completed at entry, reading and math achievement levels, receipt of any postsecondary service through a VR agency, and receipt of a postsecondary degree through a VR agency. Results from this analysis appear in Table 8 and are depicted in Figure 1. Together, these educational characteristics account for 18 percent of the variance in earnings.⁴ Among characteristics of consumers at entry to VR, both receipt of special education services (standardized weight of -0.10) and math achievement level (standardized weight of 0.24) are significant predictors of earnings: Individuals who received special education in high school earn significantly less than other individuals, while those who have relatively higher levels of math achievement earn significantly more. As Hayward and Schmidt-Davis (1999) report, youth who received special education in high school have higher rates of significant, congenital disabilities, including mental retardation and other developmental delays; these characteristics are likely to account for lower earning levels among individuals who received special education.⁵ Both receipt of a postsecondary service through a VR agency (standardized weight of 0.13) and receipt of a postsecondary degree (standardized weight of 0.12) significantly predict higher earnings, even after other educational characteristics are taken into account.

Interestingly, in this model, math achievement level, rather than other characteristics at entry, makes the largest contribution to predicting earnings at closure among the educational variables that we tested, while special education status is also a significant (negative) influence. While receipt of

Table 7
Correlations between Earnings and Educational Characteristics, Functional Status, and Attitudinal Characteristics

Characteristic	Correlation with Earnings
Educational Characteristic	
Years of education	0.17*
Reading achievement	0.29*
Math achievement	0.34*
Special education	-0.25*
Receipt of postsecondary education service	0.08*
Receipt of postsecondary education degree	0.06*
Functional Limitation at Entry	
Gross motor function	0.01
Cognitive function	0.08*
Personal care function	-0.01
Attitudinal Characteristics	
Self-esteem	0.07*
Chance	-0.06
Powerful others	-0.07*
Internality	0.04

*Indicates that the correlation coefficient is significant ($p < .05$).

Source: VR Longitudinal Study, November 1999

Table 8
Relationship of Educational Experiences and Post-VR Earnings ($R^2 = .18$)

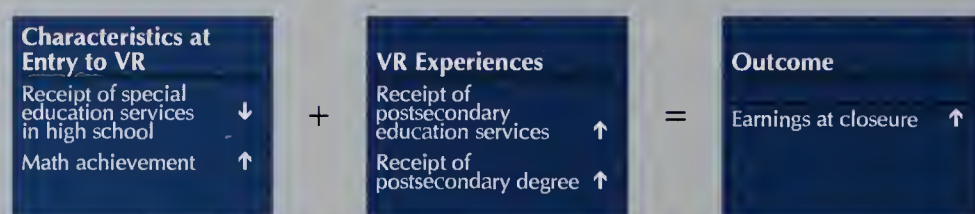
Factor	Unstandardized Weight	Standardized Weight
Receipt of special education services in high school	-0.07	-0.10
Number of years of education completed at entry to VR	NS	NS
Reading achievement ^a	NS	NS
Math achievement	0.03	0.24
Receipt of postsecondary service through VR agency	0.10	0.13
Receipt of postsecondary degree through VR agency	0.13	0.12

All listed values are significant at $p < .05$.

^a Reading and math achievement levels are highly correlated (.77) with each other, probably because most measures of math achievement involve reading skills. This strong association is likely to be the reason that only math achievement is a significant predictor in this model.


Source: VR Longitudinal Study, November 1999

Figure 1
Relationship of Educational Experiences and Post-VR Earnings



a postsecondary service and of a postsecondary degree also contribute significantly to predicting earnings, the magnitude of their influence is much smaller than that of grade level achievement in math. (As noted previously, reading and math achievement are highly correlated, probably accounting for the fact that reading achievement does not appear to be a significant predictor in this model.) These results suggest that, while receiving postsecondary education is an important step towards achieving financial independence, improving basic skills may be equally important, particularly to the extent that such improvement increases VR consumers' ability to benefit from further education and training.

In sum, these findings suggest that VR agencies may need to offer serv-

ices to improve basic skills to consumers whose basic skills are low when they enter VR. Such services might well improve consumers' ability to enter better paying jobs as well as increasing their likelihood to qualify for postsecondary education services or additional training that may further enhance their later labor market success. 

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Notes

1. The longitudinal study involved a complex sampling design that necessitates the use of specialized statistical software for significance testing and modeling; we used SUDAAN for these analyses.

2. Since SUDAAN does not compute correlation coefficients, we used SAS to create this correlation matrix and to test each coefficient for significance. Thus, this analysis does not fully take into account the sampling design of the study.

3. The assumptions of multiple regression modeling require that the dependent variable (i.e., earnings) have a normal distribution. When this assumption is violated, researchers typically transform the variable into a form in which it has a normal distribution. In this case, since earnings were not normally distributed, we calculated the natural logarithm of each value and conducted the regression analysis using the transformed earnings as the dependent variable. Therefore, the unstandardized and standardized weights presented on Table 8 refer to the effects of the independent variable on the natural logarithm of earnings rather than on actual earnings.

4. We note that this model achieves a level of prediction that is quite strong, accounting for nearly 20 percent of the variance in outcomes. This level of prediction is unusual in social science research, especially when several of the measures were obtained at much earlier timepoints.

5. While the effect of receiving special education on earnings is negative in this model, further research may well show that receiving these services actually improves basic skills levels and employment outcomes.

Postsecondary Education and Employment of Adults with Disabilities

Americans with disabilities still face gaps in securing jobs, education and accessible public transportation and in many areas of daily life. Less than 30 percent of working age adults with disabilities have even part-time employment, compared with nearly 80 percent of the general population. We propose that better access and outcomes in postsecondary education will improve not only the rates of employment for adults with disabilities but also the quality of employment. The National Center for the Study of Postsecondary Educational Support, University of Hawaii at Manoa, recently funded by the National Institute on Disability and Rehabilitation Research, will seek to identify the nature and scope of existing supports and their effectiveness, with a specific look at technology and the center will also examine the connection between outcomes and supports in postsecondary education with those in the workplace.

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In 1998, the National Organization on Disability (NOD) surveyed 1,000 adults with disabilities in the United States and found that only 29 percent of adults with disabilities, ages 18–64 years, worked full- or part-time, compared with 79 percent of the nondisabled population. It also reported that 20 percent of adults with disabilities have not completed high school, in contrast to 10 percent of adults without disabilities and other findings regarding the different levels of access and success in obtaining employment, education,

public transportation, and many other necessities of daily living.

The Rehabilitation Act Amendments of 1992 (PL 102–569) clearly acknowledge that “disability is a natural part of the human experience and in no way diminishes the civil rights of individuals.” Despite this legislation, people with disabilities continually encounter various forms of discrimination in such critical areas as postsecondary education, transportation, healthcare, and employment (Walker, 1996). It is important that we understand their present and future needs for full participation in society. This article will examine published literature on emerging strategies to enhance access to and

participation in postsecondary education. Further, it will describe the development of the National Center for the Study of Postsecondary Educational Supports, University of Hawaii at Manoa, to support the outcomes for students with disabilities.

The passage of the Americans with Disabilities Act (ADA) in 1990 (PL 101–336), along with the recent reauthorization of the Individuals with Disabilities Education Act (IDEA) Amendments of 1997 (PL 105–17), has led to an expanding social awareness of disability issues and, increasingly, to students with disabilities seeking access to colleges, universities and vocational technical programs (Benz, Doren & Yovanoff, 1998; Stodden, 1998). The number of postsecondary students reporting a disability has increased dramatically, climbing from less than 3 percent in 1978, to 9 percent in 1994, to nearly 19 percent in 1996 (Blackorby & Wagner, 1996). Since 1990, there has been a 90 percent increase in the number of postsecondary programs offering opportunities for adults with disabilities to continue their education (Pierangelo & Crane, 1997). Nonetheless, the enrollment rate of people with disabilities in postsecondary institutions is still 50 percent lower than that of the general population. This gap in educational attainment significantly and adversely affects the long-term em-

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ployment prospects for people with disabilities.

Impact of Postsecondary Education on High Quality Employment

Over the past 20 years, changes in the nation's labor market have increased the importance of postsecondary education as a factor in the job market, particularly high quality employment and long-term career opportunities. Students who continue their education after high school maximize their preparedness for careers in today's changing economy as they learn the creative thinking and technical skills necessary to take advantage of current and future job market trends.

Adults with disabilities are negatively and disproportionately affected by changes in general employment trends. For example, employees with disabilities experienced a larger relative layoff in manufacturing than employees without disabilities (Yelin & Katz, 1994). Thus it appears that people with disabilities, as with other minority groups, often face labor market liabilities which place them in the position of being the last-hired and the first-fired (Trupin, Sebesta, Yelin, & LaPlante, 1997). Indeed, disability may combine with gender, age and race to place some people with disabilities at an even greater disadvantage in the job market, especially in relation to high quality employment options.

With the changing job market, access to postsecondary education becomes more critical to the pursuit of high quality employment positions. A clear, positive relationship among disability, level of education and adult employment has been firmly established in numerous studies (e.g., Benz, Doren, & Yovanoff, 1998; Blackorby & Wagner, 1996). In fact, employment rates for people with disabilities demonstrate a stronger positive correlation between level of education and rate of employment than appears in statistical trends for the general population (Stodden, 1998). In 1996, U.S. Census Bureau statistics indicated

labor force participation rates at 75 percent for people without a high school diploma, 85 percent for those with a diploma, 88 percent for people with some postsecondary education, and 90 percent for those with at least 4 years of college. By contrast, only 16 percent of people with a disability and without a high school diploma currently participate in today's labor force. However, this participation doubles to 30 percent for those who have completed high school, triples to 45 percent for those with some postsecondary education and climbs to 50 percent for adults with disabilities and at least 4 years of college (Yelin & Katz, 1994).

These figures help portray the huge cost of failure to support people with disabilities in postsecondary education programs, both to these individuals as well as to society. In order to provide needed supports, institutions need to: (a) focus attention on overcoming barriers to high quality employment for people with disabilities, and (b) identify educational accommodations and supports, including assistive technologies, that promote the successful completion of postsecondary education programs.

Barriers to Postsecondary Education

While the data for students with disabilities show a consistent positive correlation between high quality employment prospects and higher levels of education, as a population their postsecondary education enrollment levels—although on the rise—remain low in comparison to the general population. For example, 25 percent of students with disabilities age 14 or older, as compared to only 12 percent of nondisabled students, do not even complete high school (OSEP, 1996). Of those who graduate, 19 percent of students with disabilities, in contrast to 56 percent of students without disabilities, attend a postsecondary school within the first 2 years of leaving high school. Three to five years after high school, 27 percent of students with disabilities, as opposed to 68 percent of students without disabilities, attend some form of postsec-

ondary education (Blackorby & Wagner, 1996).

In 1996, the Office of Special Education Programs published *Results of the Second PASS Field Test*, an extensive study of the types of services youth with disabilities require in their transition to adulthood and postsecondary programs. Eighty percent of the youth surveyed required some type of case management service. Assistance and training related to the areas of communication, including speech and language therapy, interpreter services, reader services, Braille training, and tactile interpreting services were cited as primary needs by over a third of the total sample.

Even with these supports to their primary needs, students with disabilities face a host of systemic, sociocultural, financial, and personal factors that contribute to low postsecondary enrollment rates. One of the first studies concerning implementation of ADA found that students with disabilities have a continuing need for information and technical assistance in postsecondary education programs; minorities with disabilities are not being adequately served; and people with certain disabilities are not being helped by the current levels of ADA implementation (Pfeiffer & Finn, 1997).

Other social and cultural factors continue to play a major role in discouraging students with disabilities from pursuing higher education. Media stereotypes tend to depict people with disabilities as victims employed in low-skill jobs. People with disabilities continue to be poorly represented among faculty, staff and education administrators, thus depriving students with disabilities of role models for postsecondary success (Grosz, 1998). All these factors, in combination with low expectations from teachers, counselors and sometimes even parents, create powerful psychological obstacles to the pursuit of higher education.

Even when students overcome barriers to enrollment in postsecondary education, disturbing evidence suggests that many of them experience difficulty staying in and completing their programs of study (Blackorby & Wagner, 1996). Failure to provide appropriate

academic development services, supports, and programs for students with disabilities may cause them to achieve grade-point averages well below that of their nondisabled peers which, in turn, may hasten their withdrawal from postsecondary settings. Also, students with disabilities who earn a tangible certificate or degree take considerably longer to finish than nondisabled students. Clearly, students with disabilities need more and better services, supports and programs, both to access postsecondary education and to be successful in this setting.

Regrettably, there is virtually no current research regarding the differential effects that various accommodation services, supports and programs have in relation to postsecondary education access, participation and long-term outcomes such as student retention, graduation rates and high quality employment opportunities (Tindel et al., 1998). As Gajar (1998) chides, "The recent influx of students with disabilities into postsecondary settings has precluded the establishment of both a body of proven practices and a clear relationship between practices and outcomes. Services have evolved sporadically and programs have been pieced together in a haphazard manner" (p.388). It is essential that some basic data-based understanding of these issues be established through research. Studies need to be conducted not only on the characteristics and needs of the students with disabilities found in various postsecondary settings but also on the unique characteristics of the postsecondary settings.

Self-Determination: Preparing for High Quality Employment

Transition from secondary to postsecondary education for students with disabilities is complex and challenging. The differences between high school and postsecondary environments are more than cosmetic (Gajar, 1998). Students with disabilities graduating from high school move from a protective environment in which school personnel are legally responsible for identifying and providing appropriate

services under IDEA to an environment in which the students are expected to request specific accommodations under Section 504 of the Rehabilitation Act and under ADA.

Under Sections II and III of ADA, postsecondary institutions are "required by law to provide any reasonable accommodation that may be necessary for those with disabilities to have equal access to educational opportunities and services available to nondisabled peers, if requested." Unquestionably, postsecondary students are charged with the bulk of the responsibility for initiating, designing and ensuring their own educational accommodations. It is their responsibility to inform school officials of their disability, provide documentation of the disability and propose viable options for meeting the unique accommodation needs specific to their disability. Thus, for students with disabilities to access, participate and perform successfully in postsecondary programs they must be personally responsible for linking any accommodations they may require to their course of study. So, self-advocacy and self-determination—the abilities to express one's needs and to make informed decisions—are considered to be some of the most important skills for students with disabilities to have before beginning their postsecondary education experience (see Benz et al., 1998, and others). The role of self-advocacy in determining the success of postsecondary students with disabilities is a necessary area of study for researchers.

Decreased contact between teachers and students, increased academic competition, changes in student support networks, and a greater expectation that students will achieve on their own—all add to the difficulties of making a successful transition to a postsecondary education program. Furthermore, in contrast to high school services to students with disabilities, postsecondary services, supports and programs vary extensively across states as well as campus-to-campus; are generally not well-developed programmatically; and tend to lean toward advocacy, informational services, or

remediation of content rather than accommodating areas necessary for independent learning and self-reliance (Reis, Neu & McGuire, 1997).

Current Status of Postsecondary Educational Supports for Students with Disabilities

Though variable in quantity and quality, support services to students with disabilities are available at most of the postsecondary education institutions in the United States. Required to meet access mandates of the 1977 passage of Section 504 of the amended Rehabilitation Act of 1973, and more recently, under ADA, schools have had to ensure that the programs they offer, including extracurricular activities, are accessible to students with disabilities. Postsecondary programs have done this in a number of ways, such as by providing architectural access, aids and services necessary for effective communication and by modifying policies, practices and procedures.

Buildings constructed or altered after June 3, 1977, have had to comply with the relevant accessibility code required by Section 504 of the Rehabilitation Act and, after January 26, 1992, by ADA. Qualified interpreters, assistive listening systems, captioning, TTYs, qualified readers, audio recordings, taped texts, Braille materials, large print materials, materials on computer disk, and adapted computer terminals are examples of auxiliary aids and services that provide effective communication. Legally, such services must be provided unless doing so would result in a fundamental alteration of the program or would result in undue financial or administrative burdens.

One of the most challenging aspects of modifying classroom policies or practices in postsecondary programs is the planning and preparation that is necessary. The difficulty lies in anticipating students' needs and preparing to meet those needs in advance. The actual modifications themselves may be relatively simple and inexpensive. Examples include:

- rescheduling classes to an accessible location;
- early enrollment options for students with disabilities to allow time to arrange accommodations;
- substitution of specific courses required for completion of degree requirements;
- allowing students to use note takers or to record lectures;
- allowing service dogs in the classroom; or
- arranging for appropriate accommodations for test taking.

The only time when such modifications of policies and practices would not be required is when they would fundamentally alter the nature of the activity or create unreasonable costs.

It is important to remember that supports and services provided by postsecondary institutions are often relatively new and, thus, not yet well known by faculty members. Faculty and other stakeholders, therefore, may find it difficult to accommodate students simply because they lack an understanding of the students' needs or familiarity with campus services. Moreover, some students elect not to disclose their disabilities in order to avoid being labeled "disabled" while on campus. Unfortunately, students who fail to identify themselves as "disabled" are often unable to access many of the supports designed to get them closer to having equal—rather than special—access to education (Gordon & Keiser, 1998).

The Research Agenda

Although a wide array of supports are provided for students with disabilities, understanding which specific accommodations are appropriate to the student and under what conditions these accommodations may be applied are issues that continue to dominate postsecondary conversations regarding students with disabilities. Definitions of what supports are "appropriate" vary extensively. Research programs must seek to identify the most promising strategies, technologies, services, supports, and programs for (a) facilitating

successful transition of students with disabilities from secondary to postsecondary settings, (b) improving student performance and graduation rates within those settings and (c) promoting personally satisfactory high quality employment outcomes.

Given that most disability-related services are a relatively new requirement within the postsecondary education environment and the likelihood that a student will run into obstacles when attempting to set up necessary support services, there is clearly a need for research to address such questions as:

* To what extent is the requirement that a person disclose his or her disability in order to obtain services a deterrent to postsecondary enrollment and completion?

• Are vocational rehabilitation or other funding sources for services not covered under ADA or Section 504 of the Rehabilitation Act readily available to postsecondary students?

• What kind of impact have various services and supports, including various assistive devices, had on students' access, participation, performance, and completion of postsecondary education?

• What are the systemic obstacles to service provision?

• To what extent does helping students develop self-advocacy and self-determination skills assist in the transition into postsecondary settings and student success within the postsecondary setting?

• To what extent do educational institutions provide transitional support to graduates as they attempt to enter high quality employment settings, and how does this affect employment outcomes?

• Which of the various services available to postsecondary students with disabilities do they—the consumers—find most effective?

• How would they like to see the services delivered?

• How can postsecondary institutions accommodate student needs in ways that are empowering for students as well as being efficient and effective at the institutional level?

Development of a National Center

The Center on Disability Studies/University Affiliated Program, at the University of Hawaii, Manoa, has undertaken in collaboration with the National Institute on Disability and Rehabilitation Research to establish a Rehabilitation Research and Training Center (RRTC) for the Study of Postsecondary Educational Supports. The purpose of this national research center is two fold:

• to explore ways to increase access to and improve outcomes for students with disabilities, in a variety of postsecondary educational settings and

• to directly involve students with disabilities, families, educators, and other support people in research activities.

The center is focusing on the study of current support practices and models of delivery and identifying barriers to educational practices, disability-related services and transitional assistance. Further, it is providing training and information to education support personnel, public and private rehabilitation personnel, career placement specialists, and students with disabilities. The center works within the following goal areas:

• To examine and evaluate the current status of educational supports, including: individual academic accommodations, adaptive equipment, case management and coordination, advocacy, and personal counseling and career advising;

• To identify effective support practices and models of delivery that contribute to successful access to and completion of postsecondary programs;

• To identify specific barriers to the provision of disability-related services including policy and funding requirements;

• To assess effectiveness of promising educational practices and disability-related services that are important to career mobility and success in the workplace;


• To test the effectiveness of specific models of delivery that are believed to

increase the accessibility of educational supports and technologies;

- To identify the types of educational and transitional assistance that postsecondary programs provide to improve academic performance and subsequent success in the labor market; and

- To provide training, technical assistance and information to education support personnel, public and private rehabilitation personnel, career placement specialists, and students with disabilities based on the findings of the center and to implement a consumer-driven empowerment evaluation plan for assessing the RRTC's progress in achieving its goals.

Conclusion

Students with disabilities face administrative, social and cultural barriers to accessing and succeeding in postsecondary education programs, and the lack of higher education adversely affects employment options. A systematic research approach such as that undertaken by the RRTC on Postsecondary Educational Supports can help reduce these barriers and has the potential to dramatically improve the participation of people with disabilities in high quality employment. While the value of attaining higher levels of education may not be entirely quantifiable, graduates of postsecondary education institutions can expect to earn at least \$250,000 to \$600,000 more over their lifetime than high school graduates (High Hopes, 1998). The poverty levels endured by one in three Americans with disabilities (NOD, 1998) are unconscionable. These levels plummet from 50 percent for high school dropouts to 15 percent for adults with disabilities with college degrees (Stodden, 1998). Unfortunately, in spite of some relative growth, the NOD (1998) report indicates that, for students with disabilities, access to postsecondary education and high quality employment continues to fall substantially below the levels attained by their nondisabled peers. 

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Assisting Adult Educators in Preparing Individuals with Disabilities for Employment

Because many consider a high school diploma to be a minimum requirement for entry into a permanent, well-paid occupation, lack of a diploma is a major barrier. Students with disabilities are disproportionately over-represented among the students who leave high school without a diploma. One of their best options is to attend an adult education program and work on a General Education Development (GED) diploma. Some estimates suggest that students with disabilities comprise as much as 30 percent of the adult education population (Hall, 1997). While federal legislation mandates accommodating the needs of persons with disabilities, adult education programs have had difficulty meeting this challenge. This article reviews the adult education option for students with disabilities and describes some of the work at the University of Kansas to assist adult educators in preparing participants with disabilities for the employment setting.

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Jean P. Hall, M.S.
Kathy Parker, M.S., OTR

According to governmental prevalence estimates, the number of persons with disabilities in adult education programs ranges from 6 percent to more than 30 percent (U.S. Department of Education, 1992). Their disabilities are as varied as developmental disabilities, learning disabilities, severe emotional disabilities, mental retardation, vision impairments, hearing impairments, arthritis, spinal injury, heart trouble, and diabetes. Hall (1997) and White and Polson (1999) reported that, on the basis of national surveys, adult

educators estimated 31 percent of the adults they served had a disability and 19 percent had verified disabilities. These adults, whose disabilities impact their educational achievement, are disproportionately overrepresented in populations of school dropouts, incarcerated individuals, mental health clients, and the unemployed. Conversely, they are underrepresented in postsecondary education enrollments, vocational training programs, the population of adults living independently, and in the American work force (Edgar, 1987; Horn & Berktold, 1999; Sitlington, Frank, & Carson, 1993). Thus, disabilities impact people in many areas of their lives, while accommodations rep-

resent an important way to lessen the impact and improve the quality of life for persons with disabilities.

This article reviews alternative frameworks for understanding accommodations and reports the findings from a national demonstration project directed at improving adult education services for learners with disabilities.

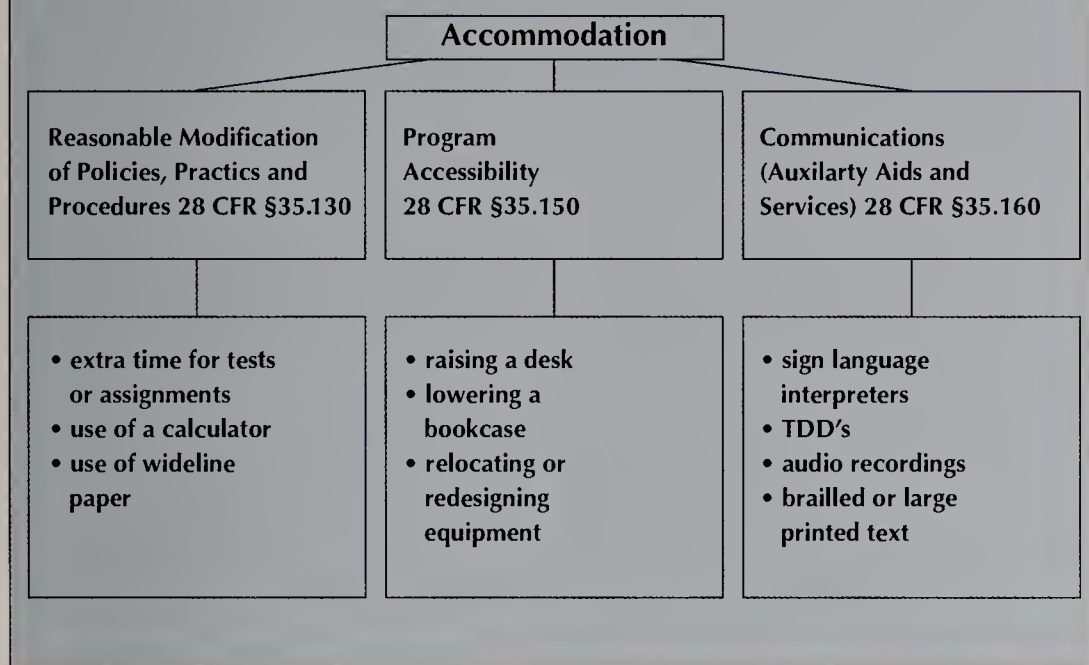
Accommodations in Definition and Practice

A variety of alternative frameworks are available for understanding "accommodations." These frameworks include legal, educational, programmatic (e.g., GED Test Service), and occupational therapy perspectives. A basic understanding of these alternative frameworks can help service providers and policymakers develop an integrated perspective that can benefit learners and employees.

Legal framework. Legislation of the past decade, including the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act, the Carl Perkins Act, and the Americans with Disabilities Act (ADA), reflects a strong commitment to meeting the needs of adults with disabilities in education, training, community facilities, and the work force. As a result of such legislation, assurance of reason-

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Figure 1
Accommodation Under the Title II ADA Framework



able and appropriate accommodations in educational, community and employment settings is mandated, including adult education. The distinctions that exist among these laws and their supporting regulations are important to adult education. Excellent reviews of these laws are available, or one could read the laws (Barr, Hartman, & Spillane, 1995; Brinckerhoff, Shaw, & McGuire, 1992; Hayward, Lawton, and Associates, 1990; Mellard, 1996).

Under Title II of ADA, which applies to adult education services, accommodations are organized into three broad categories: (a) reasonable modification of policies, practices and procedures, 28 CFR §35.130, (b) program accessibility, 28 CFR §35.150 and (c) communications (auxiliary aids and services, 28 CFR §35.160). This framework is represented in Figure 1 which includes examples of accommodations for each part of the regulation.

One of the important features of the ADA framework is that it introduces the concept that accommodations can be organized to address learners' different needs. For example, physical accessibility is one domain in which programs need to provide accommodations. Access to a program is the pre-

eminent requirement for a learner, but it is not sufficient. If the learner is unable to access the services, none of the other positive features of the program would make any difference. Other accommodations such as alternative communication formats or changes in policies may be needed to afford a person an opportunity to benefit from the access. So, as a legal framework, ADA alerts program staff to the learner's requirements under the law but it does not help with matching the learner to a needed accommodation.

Many people are confused about the limits of a program's responsibility. Ac-

cording to guidelines provided by ADA regulations, accommodations should (a) be based on documented individual needs; (b) allow the most integrated experience possible; (c) not compromise the essential requirements of a course or program; (d) not pose a threat to personal or public safety; (e) not impose undue financial or administrative burdens on the program; and (f) not be of a personal nature (e.g., personally prescribed devices such as eyeglasses or a wheelchair).

Educational framework. In education, "accommodations" are frequently thought of as academic-related adjustments or auxiliary aids. Ysseldyke, Thurlow and Silverstein (1994) identified four possible areas of adjustments: (a) presentation, (b) response, (c) time, and (d) setting. Mather and Roberts (1995) put the emphasis on curricular adjustments. According to these authors, accommodations are "adjustments in curricular demands that allow a student to succeed. These changes in the school environment result in the provision of equal opportunity and equal access to all students" (p. 85). Figure 2 depicts Mather's and Roberts' organization of accommodations into four categories.

The advantage gleaned from their categorization is the inclusion of "attitudinal" accommodations. Judging from comments of adult educators (Hall, 1998) and employers (Fabian, Luecking & Tilson, 1995), one of the most significant barriers is the lack of acceptance of persons with disabilities.

Figure 2
Concepts of Accommodations

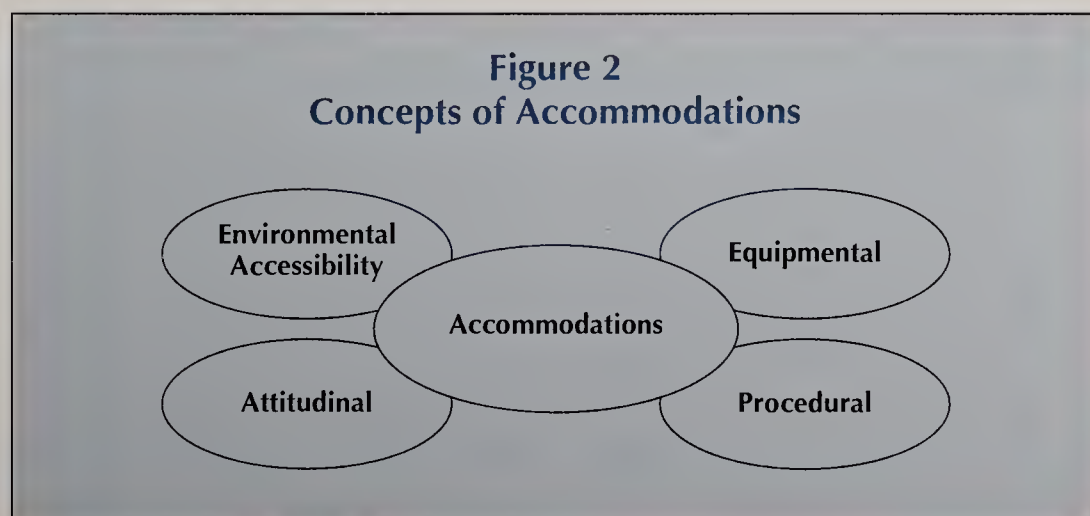
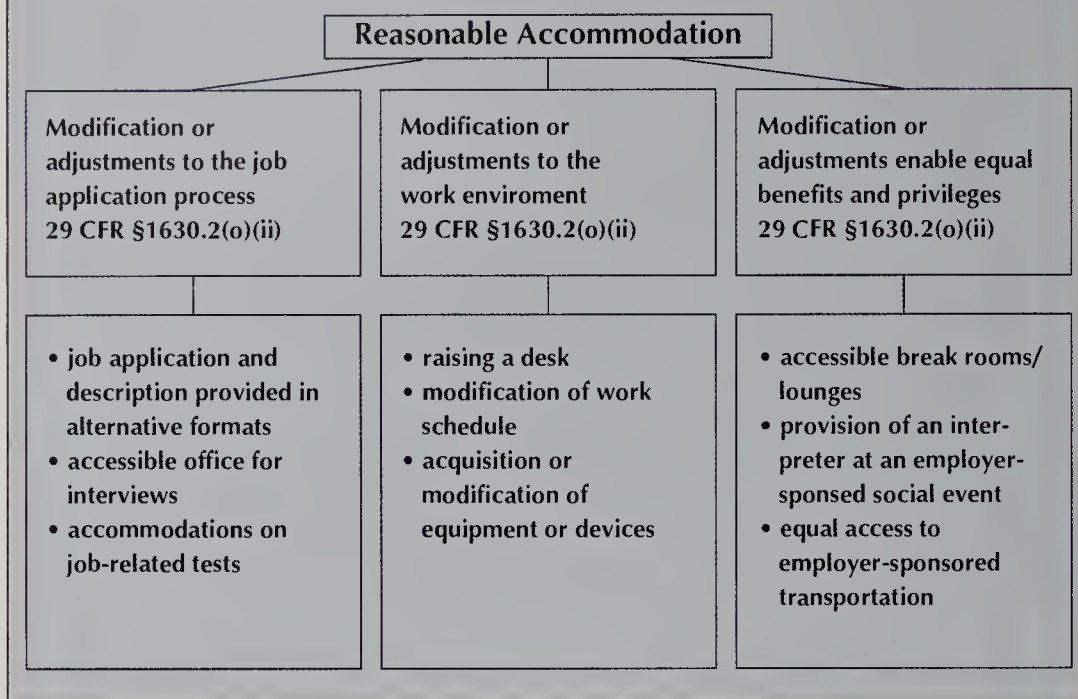


Figure 3
Accommodations Under the ADA Framework (Title I)



These negative attitudes often reflect personal fears. They (persons with disabilities) will scare off other persons we want to help; they are different from our other customers; or they need more specialized help than we can provide. Certainly if persons with disabilities are going to be integrated into society, these attitudinal issues need to be addressed. Changing such attitudes requires a much more intensive, sustained effort than what is needed for removing architectural barriers.

While accommodations are considered from a somewhat broader perspective as a means for improving personal competence in education settings (Mather & Roberts, 1995; Mellard, 1996), the employment setting focuses more narrowly on accommodations to meet ADA requirements (Dolately, 1993). Under ADA, "accommodation" means "any change or adjustment to a job or work environment that permits a qualified applicant or employee with a disability to participate in the job application process, to perform the essential functions of a job, or to enjoy benefits and privileges of employment equal to those enjoyed by employees without disabilities" (Americans with Disabilities

Act, 1990; Great Plains Disability and Business Technical Assistance Center, n.d., p. 24). Consistent with this perspective, examples of accommodations in the work setting include: acquiring or modifying equipment or devices, job restructuring, part-time or modified work schedules, providing readers or interpreters, and making the workplace accessible to and usable by individuals with disabilities. Figure 3 reflects these ADA distinctions in employment.

Programmatic framework. A discussion of accommodations frequently moves from the value of including persons with disabilities to equality and equity issues. For example, from an equity perspective one might question why is it fair to allow a person with disability extended time on a test? Doesn't such a change compromise the fairness of the test for other students who don't receive the accommodation? Other persons can persuasively argue that the change in the format or procedures for tasks such as tests results in a substantial change of the activity and, to carry the test example further, should alter the way in which scores are interpreted (Phillips, 1997, 1998). Thus, equity and fairness issues must also be considered

in the validity of changes in academic tests or assignments. Within the adult education program, test accommodations are a major issue for learners taking the General Education Development (GED) tests. Successfully completing the GED is an alternative means of earning a high school diploma. Test accommodation procedures are also confronted on other national or state exams (e.g., college placement tests, entrance exams for professional schools such as law and medical schools and certification exams).

The GED Testing Service (GEDTS), which has national administrative responsibilities for the GED examinations, provides information about acceptable and unacceptable accommodations for persons with disabilities who want to take the GED (GEDTS/ACE, 1993). Acceptable accommodations include: extra time, private testing rooms, frequent breaks, interpreters, scribes, calculators, audiocassette administration, braille, and large print. Two unacceptable accommodations are using computers for writing essays or recording responses and employing readers. While GEDTS believes that consistent interpretation of test results is paramount, that model may not be accommodating to persons with disabilities who need to complete the exam as a prerequisite to other activities (e.g., employment or entrance to a postsecondary setting).

Brinckerhoff, Shaw and McGuire (1992) cited the following examples of accommodations for postsecondary settings: changes in the length of time permitted to complete a degree, substitution of specific courses and additional time for testing. Other types of adjustments include access to taped textbooks, readers, computers, lecture notes, or other means of making oral information available in alternative forms. If educational settings allow such accommodations for meeting degree or certification requirements, other agencies (e.g., GEDTS) seemingly have a more difficult time justifying the restriction of options for qualified individuals.

While negative attitudes can significantly limit accommodations, other substantive issues are also involved—issues that are properly viewed from

perspectives of justice and the science of psychometrics. Such perspectives provide a link to the courts as a means of resolution.

Occupational therapy framework. Up to this point, the legal basis for accommodations and educational and programmatic models and related issues have been presented. In completing our research we were consistently troubled by observations and students' reports that accommodation decisions were made *for* the learner. That is, the choice of the accommodation was based on an agency's guidelines, the disability label and a process completed by the instructor. In addition, our interview and survey findings indicated that few adult educators had extensive knowledge about disability conditions and that at least a quarter of them felt uncomfortable working with persons with disabilities. What we wanted to do was to offer an alternative accommodations framework in which the learner and educator could jointly participate in the accommodation selection process and provide a formal framework for that decision process. For example, we wanted to de-emphasize the weight given to a person's disability and rather emphasize the functional needs of the individual within the adult education program. In addition, we wanted to use those assessed needs to guide the accommodation selection process in a manner in which the learner could actively participate. From our perspective then, we rejected the use of "accommodation lists" and wanted a strategy the learner and educator could use in jointly considering alternative accommodations.

Two very different models (Smith, 1993; Dunn, Brown & McGuigan, 1994) helped us achieve these goals and increase our understanding of accommodations. Roger Smith and his colleagues at the University of Wisconsin-Milwaukee had been working on the use of adaptive equipment and technology for accommodating persons, which was the first model we examined. Smith (1993) outlined two broad strategies for accommodations. One strategy focused on changes in the individual and the

second focused on environmental changes that help the person compensate for impaired human function.

The concepts of *adaptive/assistive* versus *rehabilitative/educational* are important and essential to understand. Future decisions will be based on **trade-offs** (emphasis added) between these two approaches used in occupational therapy intervention. Adaptive/assistive technologies in this classification scheme are defined as those that help an individual compensate or substitute for human function that has been lost. Adaptive/assistive technologies assume that there is a gap between the functional performance of an individual and his or her ideal performance. This gap can be partially filled through the aid of adaptive/assistive devices. On the other hand, technologies can be used not only to help compensate for loss of function, but actually to improve the function of an individual through rehabilitation or education. (p. 11)

The critical concept underlying the differentiation between these two types of technologies is that when resources are limited and there is not sufficient financial support to provide all of the needed interventions for students with disabilities, decisions will be based on whether it makes more sense to invest in environment-adjusted interventions, which include adaptive/assistive technologies, or whether it makes more sense to invest in environment-free interventions such as rehabilitation/educational technologies or direct education and therapy. (p. 12)

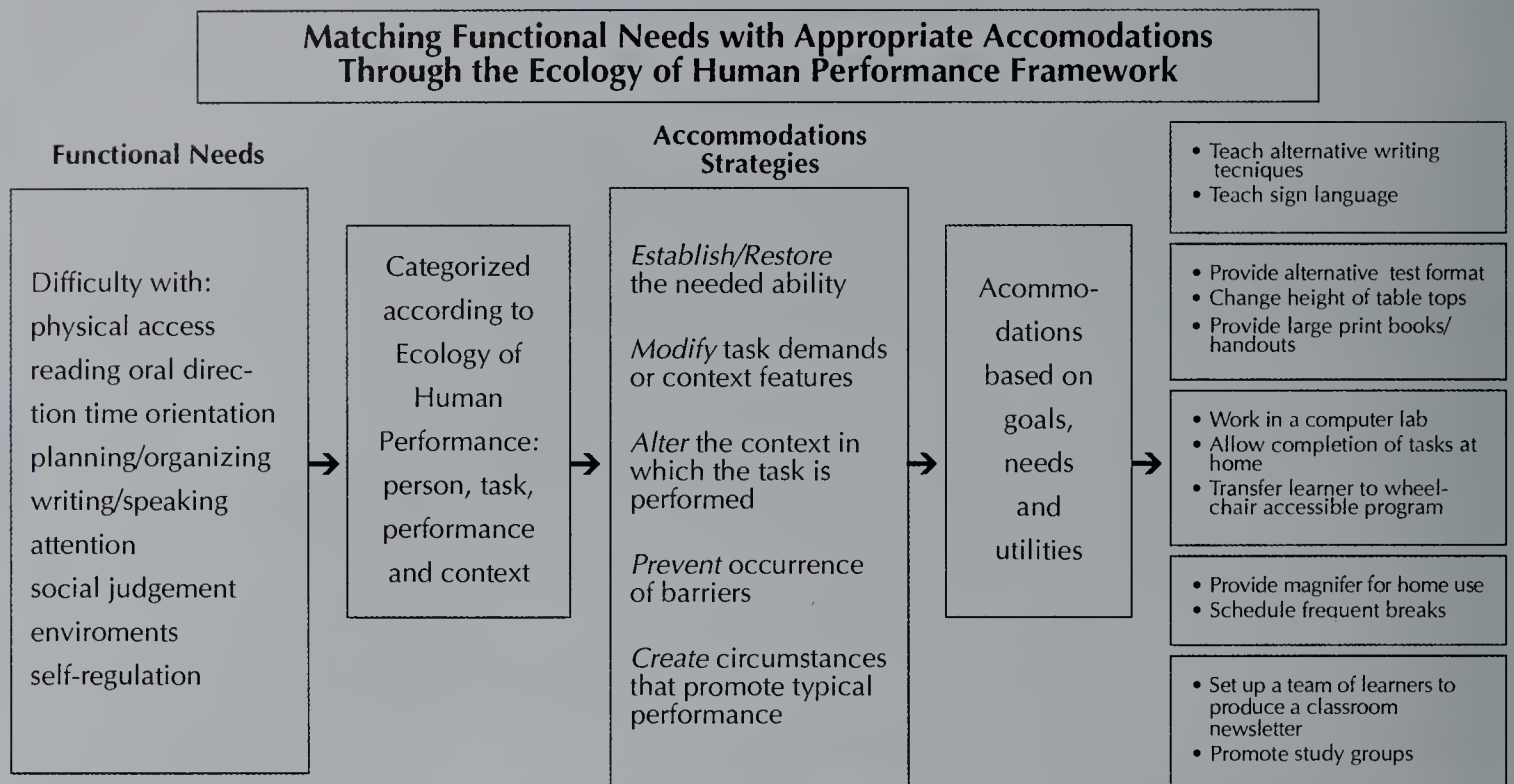
Two important concepts from their work that were especially helpful were that of (a) thinking of accommodations as organized into two approaches or strategies with unique outcomes and (b) viewing the decision about which strategy to pursue as one that involves trade-offs. Because the accommodation decision has long-term consequences, the learner needs to be involved in weighing the pros and cons of the two strategies.

The Ecology of Human Performance (EHP) framework (Dunn et al., 1994) provided the second framework for further organizing and developing ac-

commodation strategies. The EHP framework was developed by the occupational therapy faculty at the University of Kansas Medical Center. As the faculty examined evaluation and intervention relative to performance components and performance areas, they realized that the importance of context, though acknowledged in principle, had not been integrated in evaluation and intervention planning. The complexities of context and its influence on performance have been long recognized across many disciplines and, yet, have not been well integrated into a cohesive framework. "The primary theoretical postulate fundamental to the EHP framework is that ecology, or the interaction between person and the environment, affects human behavior and performance and that performance cannot be understood outside of context" (Dunn et al., 1994, p. 598). That principle then helped us understand how accommodations could be grouped into five strategies—those that: (a) establish or restore needed ability; (b) alter the context; (c) adapt or modify the task or contextual features; (d) prevent barriers; and (e) create circumstances that enhance performance. The establish/restore strategy parallels Smith's rehabilitation/educational category. The other four EHP strategies appear to us as further delineation of Smith's adaptive/assistive category. We see some advantages to these delineations by giving the practitioner and learner a framework for further analysis of contextual and task features.

Synthesizing these perspectives affords us an opportunity to change the approach of accommodating students or employees with disabilities. For example, rather than making accommodation decisions on the basis of a disability, the emphasis shifts to an analysis of the person's goals and needs; the disability *per se* is reduced in importance. Another significant change is that accommodations can be organized into a strategic framework. The five EHP strategies illustrate that accommodations have different emphases: changing the person, changing the task, and changing other contextual features.

Figure 4
Accommodations in the EHP Framework



The choice of which strategy to pursue has immediate and long-term consequences, which fits with the next point. The person becomes an integral decisionmaker in the process of choosing among the five strategies. For example, the participant identifies goals and accommodation features that are more important and those that are less important.

In our work in the adult education setting, participants identified numerous features of accommodations that were important in selecting one accommodation strategy (e.g., establish/restore, alter, adapt/modify, prevent, or create) or even one accommodation over another. Some of these features which were part of that decision process are listed in Table 1. Just as most of us can describe the features we need or want in an automobile, a person in need of an accommodation can describe the features important in that selection. Just as buying a car is consumer directed, so also should accommodation selection be consumer di-

rected. Imagine the accommodation selection process in which the discussion focuses on reviewing a list of accommodations, selecting one or two based on the person's disability, and agreeing to "give it a try." Now imagine the process and concurrent discussion when the learner and instructor discuss the learner's goals; how those goals fit with long-term plans for employment, continued education, and quality of life; and characteristics of different accommodations. The discussion changes when the learner realizes that an immediately powerful accommodation (e.g., having a scribe or reader) is also an expensive accommodation over the long run, does not develop the learner's skills in dealing effectively with such tasks, leaves the learner dependent on someone else, and will always distinguish the learner in a social setting.

One of the best features of the EHP accommodations framework is its formative, futures-directed characteristic. That is, the five EHP strategies are "ac-

commodating" for future developments. As professionals across disciplines continue to develop their understanding of disabilities and contextual features, this framework is inclusive enough for incorporating that understanding and the resulting accommodations. For example, imagine the employee or learner whose disability is a functional limitation in listening and comprehending orally presented information. As technologies are refined to allow improved listening comprehension, those technological advances can be included as one of the five strategies (e.g., adapt or create). The EHP framework encourages an analysis of personal, contextual, task, and performance characteristics and goals.

Case Studies

The following examples serve as applications of the accommodations model. These fictional learners are based on real persons enrolled in adult education programs involved in our NIDRR project's pilot and field test sites.

Table 1
Characteristics Guiding Accommodation Selections

1. Acceptance by others in the program
2. Amount of learner training required
3. Approved by test agency (e.g., GED Testing Service)
4. Availability of accommodation
5. Cost of accommodation
6. Documented in the learner's educational records
7. Ease of incorporating the accommodation into the routine
9. Expected power/benefit
10. Gain in independence
11. Instructor knowledge
12. Learner's functional need
13. Long-term benefit
14. Need for additional support by another
15. Social benefits to learner
16. Suitability for different tasks
17. Use across environments; portability

Accommodations for a learning disability. Tyrone is a 19 year old with a learning disability in the area of math calculation. Like many students with learning disabilities, the high school experience was not a positive one and he dropped out of school. He lives with his parents and is attending adult education classes to pass the GED tests and graduate from high school. He is very frustrated with "the system" and feels like he has fallen through the cracks.

After conducting an interview with Tyrone, his teacher discovered that he became overwhelmed when presented with too many math problems at once. She also noticed that he sometimes left his seat during class, which both agreed was distracting to learners and limited his ability to complete assignments. Together, Tyrone and his teacher agreed that very focused instruction on math computations and some accommodations would be initiated. In addition to specialized instruction, his apparent math disability could be accommodated by the instructor breaking the assignment into sets of tasks (adapt strategy), allowing the use of graph paper to help him align his number columns (adapt strategy) and providing frequent short breaks to prevent frustration from mounting (prevent strategy).

Tyrone eventually passed the GED practice test in math and is well on his way to completing his diploma. Now that he understands the value of such accommodations, he plans to seek an employment setting which is compatible with frequent, short breaks as a job accommodation.

Accommodations for a health disability. Linda is a 34-year-old single mother of two children. She is currently working at a minimum-wage job. She has a history of substance abuse and is diabetic. Linda wants to pass the GED tests so that she can get a better job and more successfully advocate for her son at school.

Perhaps due to her history of substance abuse, Linda seemed to have significant difficulties with remembering things. She also had a medical need to measure her blood sugar levels and eat snacks to maintain the proper levels.

With her instructor, Linda worked out a system to create a weekly calendar of assignments to help her organize her priorities and complete tasks (adapt). The calendar also gave her instructor a framework upon which to gauge Linda's educational progress and give her feedback. Linda appreciated being allowed to store snacks and insulin in the staff refrigerator.

With a letter from her doctor, Linda was able to request breaks to monitor her blood sugar during the GED exams (prevent). She has become more successful at work by keeping a calendar, and her self-esteem has increased to the level that she feels confident in meeting with her son's teachers.

Barriers to Effective Accommodations

In our statewide interviews of 23 adult educators, 80 percent reported being comfortable with providing accommodations to learners with disabilities but frustrated by limited resources to do so (Hall, 1998). This frustration was mirrored in our national survey of 622 adult programs. In that survey, adult education staff were asked to identify barriers to providing effective accommodations. The most frequently cited barriers were: limited budget (75% of respondents), limited staff (56%), lack of training (42%), and lack of resources for assessments (36%) (Hall, 1997). In speaking with program staff at our project's pilot site, we also learned that most adult educators feel that working with learners with disabilities takes too much time away from other learners. These and other barriers described below limit the ability of adult education staff to effectively accommodate learners with disabilities.

Broadly, the barriers to accommodations in adult education programs fall into five categories:

- Attitudinal
- Fiscal
- Staff Knowledge/Training
- Programmatic
- Environmental

Project activities were designed to address and ameliorate each of these barriers.

Attitudinal Barriers. The predominant attitudinal barrier to providing effective accommodations was staff members' belief that they were already accommodating learners with disabilities simply by providing individualized instruction and support. Another erroneous belief of educators was that

they simply did not have any learners with disabilities or had only a few. Subsequent project activities revealed that although about one-third of adult education participants probably have disabilities, only about one-half of that number (19%) have documentation of their disability (Hall, 1997). These attitudes were addressed by providing information and training to adult educators on the many different types of disabilities and the areas of functional need which may result.

Another troublesome finding from the statewide interviews was that learners were involved only about half of the time when accommodations were being selected for them by program staff (Hall, 1998). At least in some instances, this situation seemed to be best explained by the presence of a paternalistic, "I know what's best for you," attitude on the part of educators. This finding is notable because, in the work setting, the learner bears the responsibility for requesting an accommodation; this process is much facilitated by that person being familiar with selecting accommodations appropriate to particular tasks and the context. For this reason, a self-advocacy curriculum was included in the EHP project materials and staff development activities. The hope was that adult educators could use the curriculum as a framework to assist learners to become effective self-advocates once they leave the program. (Within the EHP framework, the curriculum could be considered as an example of the prevent strategy.)

Fiscal Barriers. In comparison to public K-12 programs, adult education programs typically receive very little funding. In Kansas, for example, annual funding per learner in adult education is approximately \$270 while annual funding per student in the K-12 program is about \$3,770, and students served under IDEA generate additional funding through federal and state entitlements. Categorical funding for K-12 students with identified disabilities increases the per student rate for these students to approximately \$5,000. No such differential funding occurs for par-

ticipants with disabilities in adult education programs.

Thus, the financial barriers to accommodations reported by adult education staff are hardly surprising. Nevertheless, these fiscal barriers can be addressed in many ways and may not be as substantial as perceived. First, staff must become aware that accommodations need not be costly. In the project's national survey of adult education programs, most of the accommodations identified as being both frequently used and effective were also those that cost very little or nothing at all (White, 1998). Most of these accommodations required no special equipment, but rather involved modifying the task for the learner. This generalization was true across disability type or functional need.

When a significant cost is involved in the provision of an accommodation, educators are encouraged to access local, state and national resources to the extent possible. These resources include state assistive technology projects, disability-specific organizations and foundations, Medicaid and Medicare, private insurance, vocational rehabilitation, workers compensation, the Veterans Administration, and special education funds (for learners younger than 22). Free services, such as those available through the Job Accommodation Network and local centers for independent living, can also assist educators in locating appropriate and low cost equipment and alternatives.

Staff Knowledge. Frequently identified as a barrier within adult education programs, staff knowledge issues incorporate a variety of content areas including knowledge about different types of disabilities, legal issues, procedures for determining effective accommodations, and relevant resources available. Each of these content areas was addressed through accommodations project products and staff development sessions. However, due to the high rate of turnover of adult education staff, such efforts need to be ongoing. Again, funding for training becomes an issue.

Programmatic. Programmatic barriers encountered during the accommodations project ranged from the lack of


physical accessibility of facilities to lack of established guidelines for program participation. Project materials described each of the five ADA administrative requirements and provided resources to assist in implementing them. Two project products, especially, seemed to be helpful to programs in meeting the administrative requirements. First, we provided a sample ADA notice for posting at programs. Many programs asked us for personalized copies of the notice. Second, we provided a trifold brochure on learner rights and responsibilities (available in English, Hmong, Russian, Somali, Spanish, and Vietnamese versions as well as audiotape and braille versions).

A more difficult issue was helping adult educators to understand the need for careful instruction in the use of accommodations and for monitoring their efficacy. Careful instruction in the use of an accommodation, especially one involving an assistive device, is important for improving its successful application. A related concern frequently expressed by the learners was that the accommodations were not monitored for effectiveness. The prevailing practice seemed to involve an informal check of whether an accommodation was working. The learners benefit from formal documentation of the accommodation's effectiveness not only in an adult education setting, but also if they should go into postsecondary settings. In the latter, the staff of the student assistance center confront a more difficult situation of justifying the use of accommodations for particular students or distinguishing why one student should have an accommodation (e.g., extended time on a test or assignment) and another student should not. A difficulty lies in striking a balance between accommodating a person's disability-related needs and gaining an unfair advantage through an accommodation (Gamble, 1993; Scott, 1994).

Environmental. This area of barriers is at least partly linked to fiscal barriers for programs. Namely, due to budget constraints, many programs take place in leased or borrowed space or in older buildings and facilities. Accommoda-

tions related to physical access or environmental modifications can be especially difficult to achieve in these settings. The project materials addressed this issue by providing a number of alternative options for accessibility and environmental modifications.

Summary

Accommodations are a critical component for improving the quality of life for many people with disabilities. Accommodations in the adult education setting are important in that they often provide the foundation for learners' requesting and successfully utilizing appropriate accommodations in postsecondary and workplace settings. The ADA provides a legal framework for understanding the rights and responsibilities of persons and institutions and for categorizing accommodations. The extensive work by Smith (1993) and Dunn et al. (1994) provides frameworks for persons with disabilities and service providers or employers to discuss alternative accommodations and their associated long-term consequences. Also, within that context the real and perceived barriers to providing accommodations can be examined and addressed through planned activities, the most important of which are increasing staff development opportunities. 

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Reading, Writing and Rehabilitation

Jerome D. Schein, Ph.D.

A counselor—let's call him Henry—sends his young deaf customer, John, for a job interview. Henry first calls the firm to make sure it has an opening and will hire a deaf worker. Henry is assured on both counts, so he is surprised when John soon returns, crestfallen. He has been abruptly rejected. Henry phones the personnel officer and is told, "We don't hire wise guys!" Puzzled, Henry asks John for more detail about what happened. John, shy about his speaking ability, handed the interviewer a note on which he innocently wrote, "I want your job."

John's story is apocryphal, though it has survived several repetitions among rehabilitation counselors. A true incident, however, happened to me several years ago. I was invited to lunch at a meat-processing plant, but the personnel officer soon made it clear that my visit was not entirely social: He wanted assistance with a deaf employee. Max was a first-rate meat cutter who knew his job so well that his limited ability to communicate did not impede his work . . . not until the company switched its health insurer. Max created such an uproar in the payroll department that he faced discharge. When I met him, Max's vigorous signing explained the source of his rage: He believed that the change meant he and his family no longer had coverage. It took me about half an hour to convince him that he still had coverage and that, indeed, the new plan provided superior benefits. Once that was established, Max went happily back to work and the company was relieved.

The two anecdotes barely illustrate the role of literacy in rehabilitation. Lit-

eracy is more than a fancy term tossed about by academics; it is a significant factor affecting the rehabilitation of all clients, especially those with weak reading and writing skills. Colloquial expressions ("I want your job") and limited ability to decipher print (in Max's case) can severely hamper gaining and retaining employment.

The Achievement of Literacy

The education of deaf students in non-specialized classes (a practice labeled "mainstreaming" or "integration") aims to increase their academic achievement. Has it succeeded? *The Annual Survey of Hearing Impaired Children and Youth* (ASHICY) conducts national testing of deaf students each year. In 1987, reading comprehension scores of 17-year-old deaf and hard-of-hearing students averaged a grade-level of 4.0. Ten years later, the average grade level for this age group fell to 3.9 (Holt et al., 1997).

The decline of 0.1 grade between 1987 and 1997 has only statistical interest. Of practical significance is the lack of improvement in reading ability over the 10-year period, in spite of the many efforts and much money which were directed during this time towards increasing literacy. For the general population, such poor reading levels signify illiteracy. To the rehabilitation counselor working with deaf consumers, this low-average reading level cautions against any assumptions about deaf people's literacy.

Deafness and Literacy

Do ASHICY's findings mean hearing loss limits literacy? Or do these results expose inadequate curriculums, lack of teacher competencies, failures to

apply new technology, or lack of motivation by educators and/or the deaf students? Probably some combination of these factors can account for the lack of improvement in reading, but the blame cannot rest with hearing loss.

Born-deaf people's first language is a visual, not a spoken, language (Schein & Stewart, 1995). In this country, American Sign Language (ASL) is the basic language on which deaf students must build. The discovery that ASL is a true language and the research that shows how quickly deaf children acquire it demonstrate that a language can be acquired without hearing it (Schein & Stewart, 1995). Other research shows language learning is inherited; it is, as the computer experts say, *hard-wired* into the organism (Chomsky, 1968; Ratner & Harriss, 1994). So learning a language is not the problem: Learning English is the problem.

Bilingualism

Research on language learning finds that bilingualism need not have a negative effect on acquiring a second language. The research on ASL as a first language finds no evidence "that the use of sign language in education interfered with the ability to develop a speech recoding strategy, or that knowledge of American Sign Language (ASL) negatively influenced the acquisition of English skills" (Lichtenstein 1998, p. 80). Data from Denmark, Sweden, Japan, Finland, and Italy also show that

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deafness does not prevent language learning, neither of the native sign language nor, in printed form, the spoken language (Furlonger & Massa, 1998; Schein & Stewart, 1995; Weisel, 1998).

Since the evidence says English literacy depends upon how American deaf children are taught, not upon their native abilities, rehabilitation professionals must focus their attention on instructional techniques. To become literate in any language, one must first know the language; then, learning to read and write that language amounts to decoding symbols representing it. Some confusion occurs between *language learning* and *literacy*. Fluency in a language differs from being able to read or write it.

Since language covers a large territory, two points apply:

- Literacy is not an all-or-nothing condition; a person may have more or less linguistic proficiency.
- There are various types of literacy, such as "computer literacy" and "scientific literacy."

Literacy can be achieved without exceptional talent. Given the opportunity, most people can learn to read and write. Persons with low IQ's can become literate, although it may take them longer to do so. Chronological age is not an insurmountable barrier: Very young children can, and often do, learn to read *before* they enter school; and adults can become literate long after they have left school (Apel & Swank, 1999; Fisher, 1998).

Motivation

Willingness to work at learning to read and write is required. When the rehabilitation counselor makes his deaf client understand how crucial literacy may be to obtaining a job, the client will likely undertake remedial instruction with more enthusiasm than before. Not all clients, of course, will respond to that incentive, so the counselor's task remains to motivate the client to study English.

Methods

One researcher argues "that a paradigmatic shift must be undertaken that uses visually based strategies for reading analogous or equivalent to those for hearing individuals" (Grushkin, 1998, p. 179). He insists that this strategy will result in more deaf students becoming successful readers.

A program specifically designed along these lines is *Structured Methods In Language Education* (SMILE). The author, Enid G. Wolf-Schein (1999), has adapted the Association Method first introduced half a century ago at the Central Institute for the Deaf, St. Louis, Missouri. In carefully designed, minimal steps, the teacher takes the deaf student through phonics-based instruction from reading to writing. Though the use of a phonics-based approach to teach deaf students is counter intuitive, SMILE has worked so well for teaching English that it now has been translated into Spanish. Its success is consistent with the view that writing is *visible speech*, which makes the method logical as well as in tune with empirical evidence (DeFrancis, 1989).

The Laurent Clerc Center at Gallaudet University, has an ambitious project to encourage parents to read to their deaf children. As simple as the prescription sounds, the study finds that parents need assistance to implement it. (For an advanced progress report, contact Dr. Linda Delk, Gallaudet University, 800 Florida Avenue, N.E., Washington, DC 20002, or via e-mail: linda.delk@gallaudet.edu) (See also Paul, 1998, and Lederberg & Everhart, 1998, for other approaches to developing literacy.)

Reading Signs

Wide-ranging research has shown that the manner in which a language is written makes a difference in how easily it is learned (DeFrancis, 1989). Chinese children learn to read their language 10 times faster in *Pinyin*—an alphabetized version of the Chinese language—than when it is written in the traditional graphemes. Similarly, Turkish is mastered more readily in the Latin alphabet than in Arabic script (De-

Francis, 1989). The Chinese and Turkish experiences should be remembered by anyone who suggests that deaf students would learn English more readily if it were presented in pictographs.

Limiting Bilingualism

Two caveats before adopting bilingualism need to be mentioned. The first is that bilingualism *impedes* language development when one of the two languages is demeaned. For example, Latino children in Los Angeles schools have more difficulty learning English when their teachers deride their native Spanish (Schein & Stewart, 1995). The second caution is that educators must not take prelingually deaf children's knowledge of ASL for granted because they use it every day. The same educators do not take normally hearing students' knowledge of English for granted, even though they use it daily. Since second language literacy will depend upon the strength with which the first language has been learned, it seems to me that studying ASL should be included in teaching English to deaf students. *The greater the first language competence, the better second language learning.*

Appraising Literacy

A counselor of deaf clients needs realistic appraisals of their literacy. Using standardized measures, such as the Stanford Achievement Tests, has been criticized because they "penalize" deaf persons. That is true, *if they are used to predict their ability to learn or to determine how well they think*; but standardized measures indicate where they stand relative to the general population. That, after all, is the measure employers will use. An employer wants to know if the deaf worker will understand printed directions or will make costly errors in operating equipment when instructed verbally; the counselor wants to know if his deaf client will need special assistance to pass a vocational course. These are fair questions, and using inappropriate measures to answer them will only penalize the deaf client.

Use of Interpreters

Few rehabilitation counselors can communicate with a deaf client in sign language. Accordingly, they are required to engage interpreters to aid them in communicating with the client. Finding interpreters and determining their qualifications are not easy tasks. First of all, interpreters tend to be in short supply. That means that too many unqualified people represent themselves as interpreters. One way to avoid them is to insist that the interpreters you use are certified by the Registry of Interpreters for the Deaf or by their state government (Stewart, Schein & Cartwright, 1998).


Once an interpreter is engaged, the counselor must become familiar with how to use the interpreter. All remarks should be addressed to the client. To facilitate that arrangement, the interpreter should be behind the counselor. In that way, the deaf person can see both, and the counselor will be looking at the deaf client when speaking. There is much more to using sign language interpreters, such as avoiding ambiguous language and overly rapid speech. Consulting with the interpreter before the client arrives permits arrangements for lighting, placement and discussion of particular problems that might arise. Once the deaf client is present, the certified interpreter will not respond to questions and will sign anything spoken by the counselor. That is why prior consultation is so valuable to a smoothly interpreted interview.

Sending an interpreter with clients for job interviews and providing an interpreter when clients or employers request one are well-justified procedures. Such instances require interpreters who have the requisite education and experience to handle employment situations. The rehabilitation counselor should also contact employers to inform them about the interpreter's role. Some personnel interviewers regard the presence of the interpreter as indicating a substandard employee. That is why some deaf clients occasionally refuse to permit an interpreter to accompany them on an interview. The

counselor can clarify the interpreter's functions and assure the employer that interpreters will not be necessary to the deaf employee's routine duties.

However, there are situations where a deaf employee may need an interpreter to perform routine duties. For instance, a deaf engineer serving as part of a working group may find an interpreter helpful during the group's meetings. In such circumstances, the deaf person who is a skilled lipreader will still be unable to function well, because following the conversation as it moves rapidly from speaker to speaker will sometimes be difficult or impossible. Advising the employer of such added expenses in advance will enable all parties to make an intelligent employment decision. For a fuller discussion of interpreters in rehabilitation, see Stewart, et al. (1998).

Summary Abstract

As rehabilitation enters the Information Age, the criticality of literacy looms large. Of all clients, those who are deaf and hard-of-hearing face the severest obstacles to entering and flourishing in a labor market that so heavily depends upon rapid, accurate communication. To date, the educational system does not appear to have prepared the average deaf student to attain English literacy. Therefore, rehabilitation must undertake the unfinished task of preparing its deaf clients for the new millennium. The evidence presented here suggests that this task can be successful and that deaf clients can achieve literacy, but that to do so will demand strong efforts to motivate them and improved methods to teach them. 

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NEW PUBLICATIONS AND FILMS

Aging in Place: Designing, Adapting, and Enhancing the Home Environment.

Ellen D. Taira and Jodi L. Carlson, editors. The Haworth Press, Inc., 10 Alice St., Binghamton, NY 13904-1580. Telephone: 1-800-HAWORTH. Softcover, 148 pages, \$19.95, U.S.; \$24.95 outside U.S., Canada, and Mexico. Hardcover, \$49.95, U.S.; \$60.00 outside U.S., Canada, and Mexico. ISBN: 0-7890-0989-7.

Designed as a guide to understanding the needs and latest trends in organizing the living space of elderly people, this book provides access to several studies on elderly people's environmental needs and preferences in regard to modifications in personal and public dwellings. Professionals in this field write on topics such as: "The Universal Design Home: Are We Ready for it?" "The Role of Occupational Therapists in Home Modification Programs at an Area agency on Aging," "The Case for ADA Accessibility Guidelines for the

Elderly," "A Key to Aging in Place: Vision Rehabilitation for Older Adults," "Using Home Modifications to Promote Self-Maintenance and Mutual Care: The Case of Old-Age Homes in India," "Does Quality of Life Vary with Different Types of Housing Among Older Persons? A Pilot Study," "Maintaining Independence Through Home Modifications: A Focus on the Telephone," and "Home Modifications for the Elderly: Implications for the Occupational Therapist.

Traumatic Brain Injury Rehabilitation. Practical Vocational, Neuropsychological, and Psychotherapy Interventions.

Robert T. Fraser and David C. Clemmons, editors. CRC Press LLC, 2000 NW Corporate Blvd., Boca Raton, FL 33431. Telephone: (561) 994-0555. Hardcover, 250 pages, \$59.95. ISBN: 0-8493-3315-6.

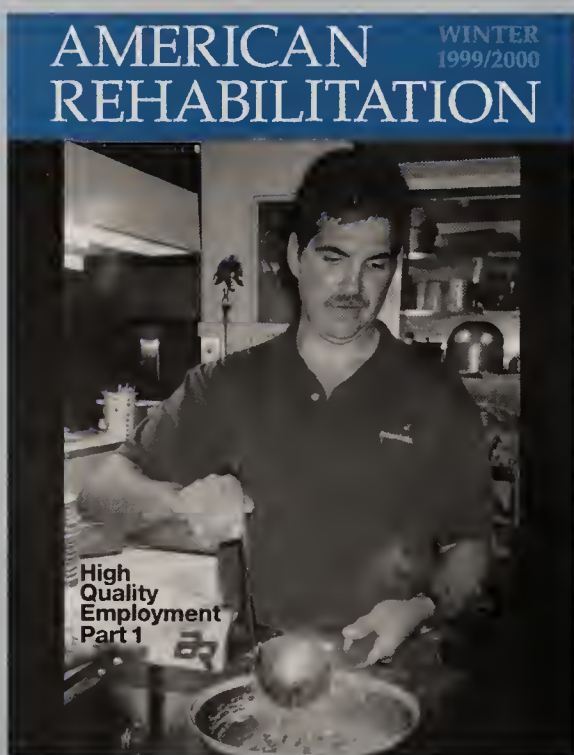
This book provides an overview of critical components of neuropsychological

information and the use of this information in vocational planning; examples of functional areas of cognition and neuropsychological assessment; the linkages between cognitive and behavioral impairments; the different categories of assistive technology; psychotherapy and behavioral interventions and successful vocational interventions; and models of work access, including methods of supported employment, the development of a tailored job coaching program, and the specifics of utilizing natural supports.

Frontiers in Head and Neck Trauma: Clinical and Biomechanical. Volume 21, Biomedical and Health Research.

N. Yogandan, F. Pintar, S.J. Larson, and A. Sances, editors. IOS Press, Inc., 5795-G Burke Centre Parkway, Burke, VA 22015. Telephone: (703) 323-5554. Hardcover, 762 pages, \$98.00. ISBN: 90-5199-369-2.

This book delivers state-of-the-art developments in head and neck trauma



If you find in *American Rehabilitation* the kind of material that informs or that is useful to you in some way, a colleague who does not receive the magazine may also profit by it. If you know such a person, fill out the blank below and send it to Editor, *American Rehabilitation*, Room 3033, 330 C Street, S.W., Washington, DC 20202-2531. We will be happy to send your friend a sample copy of the magazine.

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to neurologists, neurosurgeons, orthopedic surgeons, physical medicine and rehabilitation physicians, physical therapists, occupational therapists, chiropractors, nurses, paramedics, ER physicians, medical students, and biomedical and biomechanical engineers. This book attracts a wide range of interest from the large population of medical and physical scientists concerned with the mechanisms, treatment, and amelioration of head and neck injury. Forensic specialists involved in product analysis will also be interested.

The book begins with the basic anatomy of the adult and child head and neck, and neurologic analysis of head and neck injury. Also, included are the experimental biomechanics of head and neck injury beginning with the mechanisms of skull fracture, diffuse and focal injuries including diffuse axonal injury, and tissue level cellular injury analysis which deals with macro and microscopic analysis of tissues in the spinal cord and head. Further topics included are epidemiology of head and neck injury, costs to the public at large, vehicular and sports related injuries, the design of anthropomorphic test devices, and mathematical modeling and analysis of head and neck injury.

A select group of world experts on head and neck trauma, including professors from the world's leading academic institutions contributed to the book. Included in this group are anatomists, neurosurgeons, orthopedic surgeons, neuroradiologists, pathologists, biomechanical engineers, and scientists from the automotive industry and from the U.S. Department of Transportation.

Venus on Wheels. Two Decades of Dialogue on Disability, Biography, and Being Female in America.

Geyla Frank. *The University of California Press*, 2000 Center St., Suite 303, Berkeley, CA 94704. Telephone: (510) 642-4701. Softcover, 299 pages, \$19.95; hardcover, \$50.00. ISBN: 0-520-21716-0.

In 1976, the author began writing about the life of Diane DeVries, a

woman born with all the physical and mental equipment she would need to live in our society, except arms and legs. This book records the relationship that developed between the women over the next 20 years.

A Practical Guide to the ADA and Visual Impairment.

Elga Joffe. *AFB Press, American Foundation for the Blind*, 11 Penn Plaza, Suite 300, New York, NY 10001. Telephone: 1-800-232-3044. Softcover, 159 pages, \$39.95. ISBN: 0-89128-318-8.

Containing information on such topics as making ADA work for your business, the accommodations necessary when employing a blind or visually impaired person, accessibility in public areas for blind and visually impaired people, and staff training, this guide includes invaluable reference features like the "ADA Accessibility Guide (ADAAG)," the "Quick Guide to Getting Help on the ADA" and an extensive resource section on products, services and organizations.

This should be a valuable resource for businesses, architectural and facility planners, technical resource centers, and those involved in the visual impairment field.

Research into Spinal Deformities 2. Volume 59, Studies in Health Technology and Informatics.

I.A.F. Stokes and P. Dangerfield, editors. *IOS Press, Inc.*, 5795-G Burke Centre Parkway, Burke, VA 22015. Telephone: (703) 323-5554. Hardcover, 350 pages, \$107. ISBN: 90-5199-430-3.

This book contains the extended abstracts of 90 papers and posters presented at the 2nd Biannual meeting of the International Research Society of Spinal Deformities, which was concerned with fundamental issues relating to the detection, diagnosis, prevention and treatment of spinal deformities, especially in children. It provides readers with the latest information and scientific ideas with an emphasis on three-dimensional and morphological aspects of spine and trunk asymmetry, improved understanding

of mechanisms underlying the etiology, pathomechanism, and treatment of spinal deformity.

The International Research Society of Spinal Deformities (IRSSD) was established in 1994 to advance the study and research into spinal deformities by providing a forum for the presentation and encouragement of research relating to spinal deformity and to disseminate the results of such research.

Multiple Sclerosis: The Questions You Have—The Answers You Need. Second Edition.

Rosalind C. Kalb, Ph.D. *Demos Medical Publishing*, 386 Park Avenue South, Suite 201, New York, NY 10016. Telephone: 1-800-532-8663. Softcover, 592 pages, \$39.95. ISBN: 1-888799-43-9.

Here is the definitive guide for anyone concerned with multiple sclerosis—those who have the disease, those who share their lives with someone who has it, and healthcare professionals involved with its management. *Multiple Sclerosis: The Questions You Have—The Answers You Need* covers a wide range of topics in a question and answer format that is readily accessible and easily understood. Its format mimics the collaborative relationship between MS patients and their healthcare professionals. Experienced clinicians provide answers to the questions that they have been asked repeatedly. The questions themselves offer a model and a vocabulary for those who are not certain what questions to ask or how to ask them. Plus, readers can quickly find information about specific topics and questions based on their individual needs.

Each chapter contains a list of references and recommended reading for those interested in pursuing more detailed information on a particular topic. The guide also contains a comprehensive glossary of all terms commonly used in MS management, as well as a list of relevant resources for individuals with MS and their families. The chapter on treatments describes all medications commonly used in the treatment of MS and the management of its symptoms.

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AMERICAN Spring-Summer 2001 REHABILITATION

**High
Quality
Employment**



A Reflection on the Vocational Rehabilitation Program

Mark Shoob
Deputy Commissioner
Rehabilitation Services Administration



The wider application of the principles of quality is crucial to the creation of a vocational rehabilitation (VR) environment where we reach beyond a closure to assure that consumers have the tools they require in order to approach their working life as a continuum and a career path. In addition, we must also commit ourselves to the goal that, with each closure, we will assist each consumer to earn a living wage.

I would like to take this opportunity to discuss with readers what our research is showing us about education of VR consumers in relation to quality employment outcomes—not only the importance of higher education for jobs in the new economy but also the importance of basic education and literacy to the improvement of the single biggest indicator of outcome quality: earnings.

The Role of Higher Education in the Quality of Employment Outcomes

The Bureau of Labor Statistics projects that through 2006 most of the occupations with the highest expected number of new jobs will require higher education. Changes in the structure of the work place will require skills of adaptation rather than skills tied to specific job descriptions, implying that the individual will engage in lifelong learning, work outside a job description and adapt to changing job demands.

Labor force participation and education are highly correlative for persons with and without disabilities, with a greater correlation for persons with disabilities. The 1997 *Current Population Survey*, a joint project of the Bureau of the Census for the Bureau of Labor Statistics, indicates that, of persons with less than a high school education, 18 percent of persons with work disabilities are in the labor force, compared with almost 77 percent of persons without work disabilities. For college graduates, 53 percent of persons with work disabilities are in the labor force, compared with 90 percent of persons without work disabilities.

Providing funding for higher education to VR consumers is an investment that can lead to lifelong employment. RSA will continue to work to find innovative ways to provide you with resources to support this important work. Additional avenues available to some consumers include adult basic education programs.

What RSA's Longitudinal Study Says About Basic Skills

RSA's *Longitudinal Study of the Vocational Rehabilitation Services Program* brought into sharp focus what VR pro-

fessionals had long suspected: the higher a consumer's levels of achievement in reading and math, the higher his or her level of earnings is likely to be. According to the study's findings, consumers earning \$5 per hour or less averaged a reading level of just over grade 7 and a math achievement level of nearly grade 6.5. In contrast, those consumers earning \$7.01-\$9.00 per hour average a reading achievement level of grade 9.9 and a math level of grade 9.0.

For those consumers whose hourly wage exceeds \$9 per hour, the levels of reading and math achievement are even higher: grades 10.3 and 9.9 respectively. Reading and math achievement levels appear to be the more important factor, given the fact that the years of education completed for those consumers earning \$5 per hour or less averages 11.4 and the years of completed education for those consumers earning between \$7.01 and \$9.00 per hour is 12.3 (less than a grade level difference). For those consumers earning more than \$9 per hour, postsecondary education seems to be a factor, given that the average number of years of completed education for this group is 13.1. Still, reading and math achievement levels appear to have the greatest influence on earnings for all groups.

A corollary to the RSA study is that the higher a consumer's levels of achievement in reading and math, the more likely he or she will find employment that provides health insurance. In addition to basic earnings paid to VR consumers, the availability of health insurance for those individuals is often critical; but only 13 percent of jobs that pay \$5 or less per hour offer health insurance. Nearly 31 percent of individuals who are placed in competitive employment by a VR agency make more than \$5 but less than \$7 per hour; but only 35 percent of jobs that pay more than \$5 but less than \$7 per hour offer health insurance. For slightly higher paying jobs, the percentage that offer health insurance increases significantly. For example, 52.1 percent of jobs that pay more than \$7 but less than \$9 per hour offer health insurance.

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The weakest ink is better than the strongest memory.

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Cover Photo: Juliette Rizzo has been Director of the Communications and Media Support Services Staff, Office of the Assistant Secretary, Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education, since September 1999. (See more on Ms. Rizzo on page 36). (Photography and cover design by Geoffrey Rhodes.)

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Work-Based Learning and Students with Disabilities:

One Step Toward High-Skill, High-Pay Careers

Sheryl Burgstahler, Ph.D.

Employment in a high-skill, high-pay position is a big part of the American dream. Yet, many people with disabilities fall short of realizing this dream. A survey commissioned by the National Organization on Disability concludes that only 29 percent of those with disabilities of working age are employed full- or part-time as compared with 79 percent of those who do not have disabilities. Of the people with disabilities who are not working, 72 percent report that they would prefer to have a job. In addition, two-thirds of adults with disabilities report that their disabilities have either prevented them from getting the kind of job they would like (41%) or made it more difficult (26%) (National Organization on Disability, 1998). Equity in career opportunities is an important goal, but one not easily achieved.

Obstacles to employment in high-skill positions for people with disabilities include lack of encouragement from individuals with whom they interact, inadequate support systems and accommodations, and lack of access to technology that can maximize independence and productivity. Computer and Internet technologies can play a key role in helping individuals with disabilities overcome some of these obstacles. Blind students equipped with voice and Braille output systems can manipulate data and text in ways that were not possible in years past. With technologies such as alternative keyboards and voice input systems, individuals with mobility impairments that limit the use of their hands can gain full access to computing resources and tools and thereby perform high-level job functions side-

by-side with their nondisabled peers. Careers that exploit technology offer great potential for individuals with disabilities. Technology can also facilitate support and encouragement to individuals with disabilities through electronic communities and information resources about alternative accommodations.

Many employers face current shortages of technical talent and predict greater shortages in the new millennium. They often report their number one challenge is finding an adequate supply of talented workers. To find qualified workers, private industry, non-profit organizations and government agencies must recruit from all sectors of society. Talented prospective workers can be found among college-bound youth with disabilities. However, these students must be encouraged to enter high-tech fields, obtain academic preparation, develop self-advocacy skills, and learn the necessary job skills to successfully perform in these positions.

Work-Based Learning Experiences

The Individuals with Disabilities Education Act of 1990 (PL 94-142), revised in 1997 (PL 105-17), seeks to ensure that students with disabilities receive an education that facilitates the transition to further education and work. Similarly, the School-to-Work Opportunities Act of 1994 (PL 103-239) increases work-based and school-based learning opportunities for all students. The act creates a national framework to help states and communities create comprehensive systems to help all students apply classroom learning to high-wage, high-skill jobs or further education, and it advocates work-based learning and college preparation, explicitly mentioning stu-

dents with disabilities as a target population for program inclusion. States and communities are developing programs nationwide to meet the transition needs of all students. College and university programs also offer a wide variety of work-based learning options for students enrolled in their institutions.

A work-based learning experience is any activity that gives a person an opportunity to witness or participate in typical tasks that take place in an employment setting. Described below are a few of the work-based learning activities most commonly available to high school and college students.

Job Shadowing

Visiting a worksite and observing one or more employees performing the day-to-day duties of a job in which the student is interested can provide a valuable career exploration experience. The job shadower can learn the basic functions and experience the working environment of a specific job. A job shadowing experience can vary in length from an hour or two to a full day or more, depending on the interest of the student and the flexibility of the employer.

Internship

An internship is an intense work experience of a limited time period. A student, internship coordinator, and employer collaborate to locate an appropriate work setting for the student to accomplish planned learning activities. The participant develops

Dr. Burgstahler is the Director of DO-IT and Assistant Director of Information Systems, Computing and Communications, at the University of Washington, Seattle, WA.

work-readiness skills and performs job functions under close supervision. Some programs offer academic credit for participation in internships.

Cooperative Education

Cooperative education programs extend the classroom experience to an employment setting. They are typically offered as part of a student's specific degree program. For example, a student could work as a trainee in a software development company as part of a cooperative education experience in computer science. In a cooperative education experience a participant works in a trainee position in a field of interest and gains career-related skills. Co-op experiences are typically paid positions and usually carry academic credits.

Service Learning

Students can gain job skills as they provide a community service in non-paid, volunteer service learning experiences. Participants apply knowledge and skills while contributing to the community. Sometimes academic credit can be arranged for service learning activities. Participants gain job skills as well as references that are useful in gaining full-time, paid employment. For example, a student with a disability who is seeking employment developing and maintaining Web pages could gain experience by volunteering to develop a Web page for a place of worship or a local charity group.

Benefits of Work-Based Learning

The transition from school to work is particularly difficult for people with disabilities. Attitudinal barriers and accommodation issues are compounded by the fact that college graduates with disabilities often have had few previous work experiences. Participating in work-based learning experiences has been recognized as a contributor to positive employment outcomes for all students, including those with disabilities (Doren & Benz, 1998). School-to-work program components that have been found to predict post-school success for students with and without dis-

abilities include the emphasis on both academic and employment skills and the provision of work experiences while still in school (Benz, Yovanof & Doren, 1997; Phelps & Hanley-Maxwell, 1997).

Participation in work-related activities can help students to:

- clarify academic and career interests;
- gain academic credit
- select future courses of study;
- pay for a college education;
- develop skills in relating to supervisors and co-workers;
- test skills in a job setting;
- build a résumé;
- develop a network of potential employers; and
- develop relationships with people who can be used as references when applying for positions upon graduation.

A student with a disability gains the additional benefits of being able to practice disclosing a disability, requesting accommodations and assessing the appropriateness of specific accommodation strategies.

For employers, providing work-based learning opportunities to students allows them to help prepare workers for the next generation and also test the job skills of potential future employees. When a participant has a disability, employers also gain practice in working with an individual to create a work environment that maximizes productivity and minimizes the impact of a disability.

Society benefits when individuals with disabilities, as well as other underrepresented populations, participate side-by-side with their peers in activities that were once unavailable to them. Full inclusion in work-based learning increases the supply of skilled workers available to fill high-skill positions. Positive experiences can also reduce the most significant barrier, negative attitude, faced by individuals with disabilities pursuing challenging careers such as those in science and engineering

(*Changing America*, 1989). Full employment of people with disabilities can save billions of public dollars that are now used to support unemployed people with disabilities (*Profit from Our Experience*, 1995).

Examples of Work-Based Learning Programs

A high school student with a disability who wishes to take part in work-based learning experiences should consult with a school guidance or career counselor or call the district office to inquire about school-to-work options provided in the school district. Counselors or special education teachers can work with other staff, including rehabilitation counselors, the employer and the student to help assure that reasonable disability-related accommodations are provided. Efforts should be made to help the student gain self-advocacy and other skills that make people competitive when seeking employment.

A college student with a disability who wishes to participate in work-based learning should ask academic advisors and faculty about opportunities. Even if a formal program does not exist, a faculty member may be willing to supervise a work-based learning experience under a directed study arrangement with an interested student. The career services or cooperative education program offices, more often available on large campuses than small, can also be of assistance in locating opportunities. The campus disabled student services office can help determine reasonable accommodations. Work opportunities on campus should also be explored, and community service organizations are always looking for volunteers.

Several nationwide efforts to place college students with disabilities into work experiences that lead to high level positions are in place. For example, Entry Point! provides summer internships in private industry and government agencies to college students who are pursuing degrees in science, engineering, mathematics, and computer science. Participants are placed throughout the country in paid positions. Entry Point!

Entry Point! provides summer internships in private industry and government agencies to college students who are pursuing degrees in science, engineering, mathematics, and computer science.

was developed through a partnership between the American Association for the Advancement of Science (AAAS), IBM, NASA, DuPont, Lockheed Martin, and UNUM Insurance Company. The AAAS also coordinates Achieving Competence in Computing, Engineering, and Space Science (ACCESS), a program that provides paid summer internships at NASA for college-level students with disabilities who are studying engineering, mathematics, physical science, or computer science.

The President's Committee on Employment of People with Disabilities has two programs to support work experiences:

- the Workforce Recruitment Program for college students and
- High School/High Tech for pre-college students.

The Workforce Recruitment Program coordinates with the U.S. Department of Defense to provide summer and permanent employment for college students. Applicants are interviewed and rated according to the Federal Government rating scale. Rating information is entered into a database for participating employers to access. High School/High Tech is a network of community-based programs that prepare high school students for science, engineering and technology careers. High School/High Tech activities are unique to each program, but typically include job site visits, mentoring, job shadowing, guest speakers, after school activities, and summer internships. Bridges . . .

From School to Work, sponsored by the Marriott Foundation for People with Disabilities, is an example of another program that develops paid internships for students with disabilities while they are still in high school.

One Program's Experiences — DO-IT

Disabilities, Opportunities, Internet-working, and Technology (DO-IT) is based at the University of Washington (UW) in Seattle and is primarily funded by the National Science Foundation, the U.S. Department of Education and the State of Washington. DO-IT serves to increase the representation of individuals with disabilities in challenging fields where they have been traditionally underrepresented. DO-IT staff work with high school and college students to facilitate successful college and career transitions. They foster activities that increase skills in using computers, adaptive technology and the Internet; preparing for and succeeding in college; and transitioning from school to work. Staff also support Internet-based discussions with peers and mentors and coordinate work-based learning experiences for participants. DO-IT provides participants a myriad of opportunities for work-based learning, specifically:

- DO-IT provides both unpaid and paid work experiences to students with disabilities within DO-IT programs. For example, college students with disabilities can work as unpaid interns or paid staff during DO-IT's summer programs for teens with disabilities. High school and college students with disabilities can also engage in peer mentoring and participate in panels, presentations and exhibits hosted by DO-IT.
- DO-IT identifies work opportunities for students with disabilities on the university campus. For example, some students have worked in the UW Adaptive Technology Lab in paid student lab assistant positions.
- DO-IT partners with Entry Point!, High School/High Tech, ACCESS, the Workforce Recruitment Program,

and college-career development offices to recruit students with disabilities into these programs.

- DO-IT develops relationships with businesses and government agencies and helps recruit and support students with disabilities within their internship programs.

In all of these activities, DO-IT staff take an active role in assuring that students, mainstream campus career development providers and employers work together to make accommodations at the worksite to maximize the success of the student. In most cases, these accommodations require less effort and fewer dollars than the employer anticipated. Dan Hodge, technical recruiting manager at AirTouch Cellular, notes: "Our costs for accommodations are usually a lot less than we anticipate they're going to be." Employers are encouraged to work with the student in determining reasonable accommodations. Together they address the questions:

1. What does the task or assignment require?
2. What physical, sensory, and cognitive skills are needed?
3. What components of the task require accommodation?
4. What accommodation options exist?

A successful work experience helps a student gain confidence, insights into career options and skills in performing job tasks and working with coworkers. The employer gains confidence in making accommodations for an individual with a disability and a higher degree of comfort in fully including people with disabilities at the worksite. A successful work-based learning experience contributes to the development of positive attitudes of supervisors and coworkers about working with individuals who have disabilities.

The work-based learning activities of DO-IT are coordinated under the DO-IT CAREERS program, which is primarily funded by the U.S. Department of Education. The name also serves as an acronym of the following reminders to participants as they prepare for the world of work.

Many participants in DO-IT programs for youth have benefitted from participation in work-based learning experiences.

- "C" is for Careers. Think about what interests you. Be imaginative, then narrow down the list.
- "A" is for Academics. Determine which academic programs best suit your career goals.
- "R" is for Research. Research careers that spark your interests, maximize your strengths and minimize your weaknesses.
- "EE" is for Experiential Education. Practice job search skills. Participate in internships, service learning, cooperative education programs, and other work-based learning opportunities.
- "RS" is for Relevant Skills. Use on-the-job experiences to learn practical "real world" skills. Apply what you've learned in school to the workplace. Test which accommodations work best.

Another successful practice of DO-IT is to connect young people with disabilities with mentors who have disabilities and are succeeding in challenging college studies and careers. Mentoring occurs in person and via an electronic community on the Internet.

Student Voices

Many participants in DO-IT programs for youth have benefitted from participation in work-based learning experiences. For example, in the DO-IT Scholars Program, students with disabilities prepare for the transition to postsecondary education and careers. The goal of the program is not only to help these students make successful transitions from high school to college to

careers, but to facilitate their development as leaders in their communities as well. Students in the program are loaned computers and adaptive technology that allow them to access the computer independently, and they are provided with an Internet connection. They attend two summer study programs at the University of Washington (UW), where they experience college life and develop supportive peer relationships while gaining valuable computer, self-advocacy and work-related skills. For a third summer session they have an option to work as interns. Once scholars enroll in college and pursue careers they become DO-IT ambassadors, sharing their experiences with the younger scholars.

In 1993, high school student Randy, blind since birth, became a DO-IT scholar. Randy was loaned a computer with screen reading software and a voice output system and provided with an Internet connection that allowed him to complete school assignments without a human reader. He participated in electronic discussions with other DO-IT scholars and adult mentors, most of whom have disabilities themselves. After attending two summer study sessions at the UW, he worked as an intern the following summer. After high school, Randy majored in computer science at the Evergreen State College in Olympia. He continues to actively participate as a DO-IT Ambassador, mentoring younger students and participating in program activities.

During Randy's college career, he took part in several work-based learning experiences, in addition to the non-paid internship at DO-IT's Summer Study Program. He participated in panels at several DO-IT professional development programs. DO-IT staff helped Randy secure a 6-month, pushes than small, can also be of assistance in locating opportunities. The campus disabled student services office can help determine reasonable accommodations. Work opportunities on campus should also be explored, and community service organizations are always looking for volunteers.

Several nationwide efforts to place college students with disabilities into work experiences that lead to high level positions are in place. For example, Entry Point! provides summer internships in private industry and government agencies to college students who are pursuing degrees in science, engineering, mathematics and computer science. Participants are placed throughout the country in paid positions. Entry Point! was developed through a partnership between the American Association for the Advancement of Science (AAAS), IBM, NASA, DuPont, Lockheed Martin, and UNUM Insurance Company. The AAAS also coordinates Achieving Competence in Computing, Engineering, and Space Science (ACCESS), a program that provides paid summer internships at NASA for college-level students with disabilities who are studying engineering, mathematics, physical science, or computer science.

The President's Committee on Employment of People with Disabilities has two programs to support work experiences:

- the Workforce Recruitment Program for college students, and
- High School/High Tech for pre-college students.

The Workforce Recruitment Program coordinates with the U.S. Department of Defense to provide summer and permanent employment paid cooperative education placement in the Information Technology department at the Weyerhaeuser Company. Randy brought adaptive technology, loaned to him by DO-IT, with him to his work experience. His knowledge about his accommodation needs and the ready availability of the technology that allowed him to be independent and productive helped to make his appointment at Weyerhaeuser successful. His work-based learning experience gave him the opportunity to try out a job at Weyerhaeuser, test his accommodations in a job setting, demonstrate his skills, and develop an important contact for his first job after graduation. In fact, Weyerhaeuser, impressed with his perfor-

"Having the computer and graphics background helped make me more qualified for the position."

mance during his cooperative education experience, offered Randy a permanent, full-time position in their information technology department. Clearly, his work-based learning experience proved to be a critical step on his road to securing a high-skill position.

The following paraphrased comments from DO-IT scholars, ambassadors and mentors echo Randy's experiences, illustrate a wide variety of work-based learning options and support the value of work experiences for students with disabilities (DO-IT goes to work, 1998):

- I had a project my senior year of college where I built and maintained a Web site for my church. I'm still maintaining it even after college. It has let me gain experience through experimentation on how to build an effective Web site. It is important for any student to do this, and it is especially beneficial to people with disabilities because they sometimes need more help to overcome employers' biases.
- I had a valuable work experience when I was in high school. I worked on a project in Explorer Scouts. We formed a group that worked at a local TV station, and we actually produced six half-hour TV programs that aired on Sunday afternoons.
- Where I live, in the country by a very small town of 514 residents, there just isn't anything for me. I work on our family farm doing some of the paperwork for our finances on my computer. I guess that

is a kind of work experience and should look good on a résumé (besides providing me with a small sum of spending money).

- I am visually impaired and hearing impaired as well . . . I am currently involved in work experience programs within my school and the community. The school district has a program called "School-to-Work" and a "School-Within-a-School" program. In the past 2 years, I have been to a doctor's office, an Internet provider and a travel agency. I have gained a lot of knowledge of business management, work ethics and other work-related skills. The program teaches résumé composition, cover letter composition, business letters, some general knowledge of business law, interview practices and rules, and how to apply for a real job and use good communication skills with supervisors, staff, managers, and coworkers.
- I was an executive intern with a local meteorologist during my senior year in high school and then worked for two summers for the assistant state climatologist of Colorado. These experiences strengthened my desire to go into atmospheric science research. I also learned that connections can really help you get a job! And I practiced articulating my needs when necessary.
- During my senior year, I had an intern job at a local newspaper. I had been interested in doing some graphic work using computers for a couple of years. I had a couple of job shadows in high school that made me really consider something in this area. So this was a really good way to get my foot in the door. My internship was not a paying one, but I got high school credit for it since I did it during school hours. If you get paid, great. Now I work at Disability Support Services at my college, and having the computer and

graphics background helped make me more qualified for the position.

- I've had four work-based learning experiences. I believe it is very important for students with disabilities to have work experiences before they graduate. An internship gives students a chance to problem-solve how they will transfer an accommodation used in school to a work setting in a nonthreatening environment. It is a learning experience! You learn what works for you, and you learn what does not work for you.

Staff and employers who work with DO-IT scholars and ambassadors report the value of these experiences for students with disabilities. They confirm the importance of students with disabilities becoming knowledgeable about their accommodation needs and learning appropriate ways to discuss their disabilities as they relate to specific job tasks. Work-based learning offers a low-risk, nonthreatening opportunity to learn and practice these skills.

Although work-based learning programs abound, Julie Smallman, past coordinator of DO-IT CAREERS, notes "Students with disabilities aren't accessing these services at the rate of their nondisabled peers. Many students regard them as optional program components that aren't designed for them." Further, she points out, "Inaccessible offices and materials, lack of targeted marketing and lack of knowledge about legal issues, accommodation strategies and other disability-related employment situations on the part of career counselors and program coordinators have posed barriers to the participation of students with disabilities in campus work-based learning programs."

Recommendations

How can we assure that more students with disabilities have access to work-based learning opportunities that will lead to employment in high-skill, high-pay positions? Creative strategies must be employed to help

work-based learning program administrators, educators, parents, service providers, policy makers, funding sources, and other stakeholders work together to reach this goal.

Those who coordinate high school and college work-based learning programs are in a unique position to provide opportunities to young people with disabilities. However, few of these programs make special efforts to recruit and support students with disabilities. These programs should

- consult with special educators, disabled student services staff and students with disabilities to create programs that meet the needs of students with disabilities;
- make special efforts to recruit students with disabilities into programs;
- assure that their facilities are accessible to individuals with disabilities and that their program materials are available in alternative formats; and
- have in place policies and procedures to accommodate students with disabilities and assure that appropriate accommodations are made in their program offerings and at worksites.

Parents, educators and service providers should help students with disabilities

- develop independent living, self-advocacy and social skills that will serve them well in an employment setting;
- gain access at an early age to powerful technological tools and use these tools to maximize independence, productivity and participation in academic and work-related activities;
- maintain high academic goals and take the math, science, and other

preparatory classes they need to pursue challenging careers;

- interact with successful role models, especially college students and adults with disabilities who are successful in challenging fields of study and employment; and
- become aware of programs that help individuals with disabilities become fully self-supporting members of society (e.g., the Supplemental Security Income work incentive program).

To assure that students with disabilities gain appropriate skills and work opportunities, employers should

- make special efforts to recruit individuals with disabilities into their companies and become aware of accommodations strategies and resources such as the Job Accommodation Network service of the President's Committee on Employment of People with Disabilities, and
- help schools and work-based learning programs understand which skills and knowledge are most critical for high performance in the work force.

Conclusion

Students with disabilities face unique challenges as they transition to college and the work force. By participating in work experiences, students with disabilities gain knowledge about specific careers and skills in working with supervisors and peers, performing job tasks, and securing appropriate accommodations. Educators, service providers, government agencies, policy makers, funding sources, and parents should join forces to assure that high school and college students with disabilities have full access to a broad range of work-based learning options.



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Resources

Council for Exceptional Children
Division on Career Development
and Transition
1920 Association Drive
Reston, VA 20191-1589
Voice: (703)620-3660
TTY: (703) 264-9446
URL: <http://www.cec.sped.org>

Bridges . . . From School to Work
Marriott Foundation for People
with Disabilities
1 Marriott Drive Rm 139
Washington, DC 20058
Voice: (301) 380-7771
Fax: (301) 380-8973
TTY: (310) 380-6680
URL:
<http://www.marriottfoundation.org/>

DO-IT CAREERS
University of Washington
Box 354842
Seattle, WA 98195-4842
Voice/TTY: (206) 685-DOIT
Fax: (206) 221-4171
Spokane Office,
Voice: (509) 328-9331
E-mail: doit@u.washington.edu
URL:
<http://www.washington.edu/doit>

Easter Seals
230 W. Monroe, Suite 1800
Chicago, IL 60606
Voice: (312)726-6200
Voice: (800)221-6827
TTY: (312)726-4258
Fax: (312) 726-1494
E-mail: webmaster@seals.com
URL: <http://www.easter-seals.org>

Entry Point! and ACCESS
American Association for the
Advancement of Science
Project on Science, Technology,
and Disability
1200 New York Avenue, NW
Washington, DC 20005-3920
Voice/TTY: (202)326-6649
Fax: (202)371-9849
E-mail: lsummers@aaas.org
URL: <http://www.entrypoint.org>

High School/High Tech and
Workforce Recruitment
ProgramPresident's Committee on
Employment of People with
Disabilities
1331 F Street, NW Suite 300
Washington, DC 20004
Voice: (202)376-6200
Fax: (202)376-6219
TTY: (202)376-6205
E-mail: info@pcepd.gov
URL: <http://www.pcepd.gov>

Job Accommodation Network
West Virginia University
P.O. Box 6080
Morgantown, WV 26506-6080
Voice/TTY: (800)526-7234
E-mail: jan@jan.icdi.wvu.edu
URL: <http://janweb.icdi.wvu.edu>

National Information Center for
Children and Youth with
Disabilities
P.O. Box 1492
Washington, DC 20013-1492
Voice/TTY: (800)695-0285
Voice/TTY: (202)884-8200
E-mail: nichcy@aed.org
URL: <http://www.nichcy.org>

National Rehabilitation Information
Center
1010 Wayne Ave., Suite 800
Silver Spring, MD 20910-5633
Voice: (800)346-2742
Voice: (301)562-2400
TTY: (301)495-5626
Fax: (301)562-2401 (FAX)
E-mail: naricinfo@kra.com
URL: <http://www.naric.com/naric>

National Transition Alliance for
Youth With Disabilities
Transition Research Institute
University of Illinois
113 Children's Research Center
51 Gerty Drive, Rm. 117
Champaign, IL 61820
Voice: (217)333-2325
Fax: (217)244-0851
E-mail: leachlyn@uiuc.edu
URL: <http://www.dssc.org/nta>

National School-to-Work Learning
and Information Center
400 Virginia Ave SW, Suite 150
Washington, DC 20024
Voice: (800)251-7236
Voice: (202)401-6222
Fax: (202)401-6211
E-mail: stw-lc@ed.gov
URL:
<http://www.stw.ed.gov/index.htm>

U.S. Equal Employment
Opportunity Commission
1801 L Street NW
Washington, DC 20507
Voice: (800)669-4000
TTY: (800) 669-6820
TTY: (202)663-4494
URL: <http://www.eeoc.gov>

Math, Computers and the Internet: Better Employment Opportunities for Persons With Disabilities

In our current job market, math skills and familiarity with computers and Internet resources are becoming more and more important. For adults with disabilities, the presence or absence of these skills and competencies will greatly determine vocational choices. Assessment of math, computer and Internet skills may be very important in individual vocational planning, but people with disabilities are not using computers and the Internet as extensively as the general population. Many consumers in the vocational rehabilitation (VR) system are poorly prepared in math and computer skills. Several new tools will help individuals with disabilities, their teachers and their counselors in improving skills needed for the current job market. This article explains the need for math skills, identifies barriers to math and science education for people with disabilities and provides examples of some of the tools designed to help people use computers and the Internet to build math skills.

Susan Stoddard, Ph.D.
Jeannette Nelson

Mathematical Literacy: Important in Today's Job Market

Access to information is rapidly changing the way we do things. In the global information environment it is nearly impossible to predict what knowledge will be required for productivity and leadership in the future. Knowing how to manage and evaluate information is certainly critical to our sustained success as a nation; and knowledge of math is essential to decision making as we go about selecting and applying information to the many complex problems we face as individuals and as a society.

Educational trends, reflected in the Goals 2000: Educate America Act, the Improving America's Schools Act and the reauthorization of the Individuals with Disabilities Education Act, call for high educational standards for all students. All children are to have access to the same knowledge and the opportunity to acquire the skills they need to succeed in the high-tech workplace of the 21st century.¹ The 5-year plan of the Federal Coordinating Council for

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Science, Engineering and Technology suggests that mathematics education needs to be reformed so that all students can participate in a rich and challenging mathematics curriculum. Of particular importance is the full participation of groups underrepresented in high levels of math proficiency. But many adults who did not have this opportunity do not have the math skills they need for today's jobs.

Becoming a participant in this age of rapid technological change requires adults and children alike to develop numeracy (mathematical literacy), which involves more than basic arithmetic. The National Institute for Literacy has helped identify seven themes, which serve as the foundation for adult numeracy standards (Curry et al., 1996). This foundation of knowledge enables students to:

- find relevance or make connections between mathematics and other disciplines;
- use math to solve problems, reason and make decisions;
- communicate mathematical ideas;
- have a conceptual understanding of numbers;
- interpret data;
- understand sense and measurement (geometry); and
- recognize patterns and relationships (algebra).

These competencies allow individuals to approach problems thoughtfully and make informed decisions; they are necessary for many jobs. Understanding the relevance of math literacy to everyday life helps to make the lessons meaningful, especially for adult learners.

Barriers to Math for Students With Disabilities

Dr. Devva Kasnitz, research director of a Research and Training Center at the World Institute on Disability, describes her experience with math

"Though I am happy with my career in anthropology, I often wonder if my problems with math kept me off an equally productive path through the 'hard' physical or life science fields."

barriers: "As a child, I had disability-related manual dexterity difficulties and was not able to pursue the subject past high school. It is hard to learn math when you can't read your own handwritten figures! Though I am happy with my career in anthropology, I often wonder if my problems with math kept me off an equally productive path through the "hard" physical or life science fields" (Kasnitz, 1996).

If students with disabilities in grades K-12 receive limited or poor instruction in science and math, they are not prepared to pursue educational opportunities in technical and scientific disciplines, limiting their chances to pursue employment in these areas. Common barriers to math education include limited access to certain tools needed to learn math and a lack of teaching about how people with disabilities, and others, use math on the job and in their daily lives.

Many children with physical disabilities perform at grade level or better until their math lessons become too difficult or abstract to complete "in their heads." Normally, children accomplish more difficult lessons using pencil and paper, an option that is commonly not available to certain children with physical disabilities. As math becomes more difficult, around the 5th grade, students cannot compete with others in the classroom. While computers may help by providing a calculator function, the computer keyboard needs to be accessible, and the software needs to support the understanding of math calculations, not just show the answers. A child who falls behind in math or becomes frustrated with math may be unable to participate

successfully in other math-dependent studies such as the sciences, economics, engineering, and many computer-oriented disciplines.

Depending on a student's disability, one or more types of accommodation might be necessary to ensure math learning. For students with physical disabilities, special software may help by simulating paper and pencil. Students with disabilities that affect memory may have difficulties recalling formulas and number facts even though they may know how to apply the information to problem solving. Some students have learning disabilities that affect the ability to organize information or sequence the steps to solve a problem. Some may not be able to organize a problem until they hear it: They need auditory support. Low vision or visual perception is also a factor that affects learning mathematics since math relies heavily on visual skills such as number and operation sign recognition. Students with visual perception difficulties need to have visual distractions removed so that they can focus on one task or problem at a time.

Solutions to access barriers are not enough to ensure math achievement. The motivation to study math, and to learn, comes from understanding the relevance of math to everyday life and using math skills to solve problems at work and at home. For students with disabilities, there is also the importance of learning about other people with disabilities who are succeeding in math and science careers and applying math and science in their lives.

Levels of Math and Reading for VR Clients

The *Longitudinal Study of the Vocational Rehabilitation Services Program*, provides information on the levels of reading and math education for consumers of vocational rehabilitation in the State-Federal Vocational Rehabilitation Services Program (see Tables 1 and 2) (Hayward and Smith, 1999). Many people that apply to VR have low levels of math proficiency. And, not surprisingly, those with higher levels of math performance

are placed into higher-paying jobs. Tables 1 and 2 were prepared from data from the study; the individuals who applied for VR services were included in the data.²

In the VR population, the mean math grade level is 7.7 years, compared to 8.5 years for reading grade level. The median shows an even broader gap, in both men and women. Half the VR population reads at grade 9 or above, while for math, half reads above grade 7.

Overall, 27.8 percent of people who use VR had math levels less than sixth grade, and 26.2 percent had reading levels less than sixth grade. Over half of the population had math levels less than high school level, and only 4.7 percent had levels above 12th grade. Of these with some college-level math, two-thirds are male, one-third are female (See Table 2). Obviously, as the *Longitudinal Study* demonstrates, the educational level of these VR participants will affect the range of job choices available. People with higher competencies in reading and math will have more job choice.

Table 1			
Reading and Math Levels of Consumers in the State-Federal VR Services Program, by Gender			
		Reading Grade Level	Math Grade Level
Overall	Mean	8.5	7.7
	Median	9.0	7.0
	Minimum	1.0	1.0
	Maximum	16.9	16.9
Males	Mean	8.3	7.7
	Median	8.3	7.0
	Minimum	1.0	1.0
	Maximum	16.9	16.1
Females	Mean	8.7	7.8
	Median	9.1	7.2
	Minimum	1.0	1.0
	Maximum	16.9	16.9

Weighted estimates. Source: Unpublished data from *Longitudinal Study of the Vocational Rehabilitation Services Program*, Research Triangle Institute, NC: 1999.

Table 2						
Frequencies and Distribution of Reading and Math Levels of Consumers in the State-Federal VR Services Program, by Gender						
Frequencies	% Reading		Total	% Math		Total
	Male	Female		Male	Female	
<= 5th grade	28.4	23.7	26.2	29.2	26.3	27.8
6th - 8th	19.6	18.9	19.3	29.1	31.5	30.2
9th - 12th	41.4	48.8	44.9	36.0	38.7	37.3
> 12th	10.6	8.6	9.7	5.8	3.5	4.7
Total	100.0	100.0	100.0	100.0	100.0	100.0
Row Distribution						
<= 5th grade	58.0	42.1	100.0	56.0	44.0	100.0
6th - 8th	54.4	45.6	100.0	51.4	48.6	100.0
9th - 12th	49.4	50.6	100.0	51.6	48.4	100.0
> 12th	58.7	41.3	100.0	65.6	34.4	100.0
Total	53.5	46.5	100.0	53.5	46.5	100.0

Weighted estimates. Source: Unpublished data from *Longitudinal Study of the Vocational Rehabilitation Services Program*, Research Triangle Institute, NC: 1999.

MathPad™: Reducing barriers to math education for students with disabilities

MathPad™ is a software tool developed to provide a means for learners with physical disabilities to access the mainstream mathematics curriculum. MathPad™ provides students with physical disabilities a way to work out arithmetic problems without need for pencil and paper. MathPad™ contains accessibility features including built-in scanning, speech output, a variety of text size options, options for color and contrast, and automatic navigation to reduce keystrokes. The program makes use of other assistive technology such as an IntelliKeys and other alternative input devices. MathPad™ has been given a special needs software award by *Technology and Learning* magazine.³

MathPad™ modules supports learning addition, subtraction, multiplication, division, statistics, and fractions and provides appropriate manipulatives. Each software module is compatible with existing curricula and lessons. These tools are intended to:

- Remove barriers that students with physical disabilities encounter while interacting with mathematics curricula materials;
- Encourage students with physical disabilities to explore mathematical ideas using accessible electronic manipulatives which will enable them to link the concrete with the symbolic;
- Provide opportunities for practice and instructional feedback to accelerate mathematics achievement for disabled students;

- Improve the disposition of students with physical disabilities toward mathematics achievement;
- Increase access to, and use of, computer-based mathematics materials by students with physical disabilities; and
- Make the curriculum for learners with and without physical disabilities consistent by integrating problem sets from popular texts and published curricular materials.

MathPad™ is not a calculator. Students perform basic arithmetic problems directly on the computer. The students must decide when to borrow, carry, or show a remainder. The software has built in features that carry out these functions with a minimum number of keystrokes. MathPad™ is also useful for students who have difficulty organizing math problems, because there is a built-in structure for working on problems and showing work.

Many design features support accessibility. The software permits a student or teacher to tailor the environment to the individual needs of a student. The program provides audio feedback to students in a variety of ways. The speech function can be activated to speak the problem, to identify the row, the entry, and toolbar buttons, or other screen navigation icons. To facilitate scanning and other alternative input devices, all commands and dialog boxes have a keyboard equivalent. A student may elect to scan the toolbar buttons using either step or automatic scanning. The type size and colors on the page can be customized to meet individual needs such as high-contrast settings for students with impaired vision.

Using MathPad™ modules, students can solve computational and word problems with whole numbers, fractions, decimals, and percents and strengthen their understanding of concepts using accessible on-screen fraction circles, fraction bars and decimal grids. Currently, these tools allow students to represent or solve problems in multiple ways using both numerical and visual models. Future modules

will include algebra and geometry. By using MathPad™ on the computer, the student learns other computer skills which can be applied to other software and education experiences.

Using the Web for Learning About Math

Using the Internet to pursue educational opportunities has great potential for expanding the math skills of people with disabilities. There has been a dramatic increase in Web-based learning materials and distance education opportunities including virtual classrooms. For individuals with disabilities these resources are promising for increasing access to education and removing barriers, the least of which are transportation barriers. Now it is possible for students with disabilities to pursue education without leaving their homes or offices.

Only recently has the Internet developed as an effective tool for education, a powerful and flexible tool for delivering curriculum. Researchers and educators are continuing to experiment with the Web as a medium for delivering instruction and providing creative learning explorations.

The Internet empowers individuals to choose how they will acquire knowledge and information. For instance, one key to the success of the Internet for educational purposes is its ability to present information in a non-linear format. In contrast to reading a printed book, this non-linear approach may be very effective for adult learners who are more motivated to acquire knowledge appropriate to their own individual circumstances. Students who are encouraged to use the Web for mathematics learning will likely increase other crucial skills needed in the workplace such as reading skills, information skills and technology skills in the process.

For adult learners, math takes on greater meaning and understanding when it is directly applied in the workplace or in real-life situations. The Internet provides a wealth of resources

But some aspects of Web design limit the accessibility of a Web site for a person with a disability.

for experiential and contextual mathematics learning. Furthermore, many disability organizations and memberships have Web sites. There is a wealth of information on disability rights, disability services and useful publications. Through the use of other assistive technologies, persons with disabilities can access these materials and pursue new opportunities. But some aspects of Web design limit the accessibility of a Web site for a person with a disability. Progress is being made to make this information accessible to individuals with disabilities through a variety of means. One of the organizations concerned with this effort is The Web Accessibility Initiative Working Group of the World Wide Web Consortium (<http://www.w3.org/WAI/>). As the Web becomes increasingly accessible, a computer hooked to the Internet will bring nearly unlimited information and communication resources as close as your home, public library or school.

Using the Internet effectively has the potential to increase the capacity of people with disabilities to engage more fully in academic and employment opportunities. However, in an age of such rapidly developing information and technology, individuals without appropriate skills and access are at significant risk of being left behind. According to a recent report from the National Institute on Disability and Rehabilitation Research, the computer revolution has left the vast majority of people with disabilities behind; only one-quarter of people with disabilities own computers, and only one-tenth ever make use of the Internet (Kaye, 2000).

PlaneMath™

The National Aeronautics and Space Administration (NASA) has a commitment to advancing education in grades K-12 and has developed a number of grant programs designed to increase interest in aeronautics careers. PlaneMath™, an interactive Web site designed to teach math to students with disabilities, is a result of the NASA initiative.⁴ Students use PlaneMath™ to

solve math problems. They can also learn about role models, people with disabilities who use math and science in their jobs.

PlaneMath™ was designed to accomplish several objectives:

- To improve access to mathematics and aeronautics curricula materials for 4th-7th graders with physical disabilities;
- To improve mathematics proficiency outcomes among 4th-7th grade students with physical disabilities;
- To inspire and motivate students with physical disabilities to pursue aeronautics-related careers; and
- To increase access to, and innovative use of, digital communication and multimedia technology among students with physical disabilities.

The PlaneMath™ Web site includes 23 sets of activities which align to the National Council of Teachers of Mathematics standards (NCTM, 2000). The lessons are presented in meaningful aeronautics settings and organized into three groups: "PlaneMath Enterprises," "Pioneer Plane," and "Applying Flying." During each lesson a student uses mathematics knowledge gained earlier, while acquiring new knowledge. In addition, students are introduced to aeronautics concepts which emphasize the connections among science, technology and mathematics.

In "PlaneMath Enterprises," students solve problems designed to help them learn many of the math concepts used in aeronautics design. In "Pioneer Plane," lessons and activities are based on the experiences of flight pioneers Amelia Earhart and Jimmy Doolittle. In "Applying Flying," exercises challenge

students to find the shortest path between two cities, to learn how planes lift off, to build a kite, to calculate airplane capacity, and to perform other related activities. For each activity, the student is invited to "meet" a person with a disability who is using aeronautics and math in his or her career, including:

- Ken Iliff, Chief Scientist, NASA Dryden Flight Research Center, who has degrees in aerospace engineering, mechanical engineering, electrical engineering, and business engineering. Ken uses a wheelchair; he got polio when he was 9 years old. He was completely paralyzed at first, and now has some use of his hands and arms. Ken's job at NASA as a research engineer is to analyze how aircraft perform. Ken says "If you are trained and properly qualified in the kinds of math and aeronautics careers we have been talking about, I think you will find that your handicap is a non-issue as far as the job is concerned."
- Julie Pollitt, NASA Mechanical Engineer, who works in the wind tunnels helping researchers design and build their test apparatus. Julie uses a wheelchair. She would definitely encourage young people to attempt careers in aeronautics, saying, "The biggest challenge I've dealt with in my career--to do with my disability--has been other people telling me what I couldn't do and me having to prove them wrong . . . I would encourage young kids to follow careers in math. Math provides the basis for most technical careers."
- Eric Sheppard, assistant professor of aerospace science engineering at Tuskegee University, who wears an elbow-elbow prosthesis which he helped design. Eric says "The key thing is to be able to understand what's happening in the world through math. You might not have to use all that you learned every day, but if you have a firm understanding of math it will help you understand how the real world works . . ."

Overall, 27.8 percent of people who use VR had math levels less than sixth grade, and 26.2 percent had reading levels less than sixth grade.

- Other people that students can learn about include Neal Loving, who is a pilot and engineer. Neal, an African American, is the first double amputee who is a licensed racing pilot. Mike Smith, president of Aero Haven Flight School, also a pilot, uses a wheelchair. Mike teaches people with disabilities how to fly.

Cathy Platano, a special education teacher at Sterling Morton Elementary School (Mentor, Ohio), wrote to the PlaneMath team about her classroom experience and the importance of the role models. Her student Jimmy had a severe physical disability; he had a tumor removed from his brain and now has only partial use of his right side. He prefers using his left arm for activities. Cathy introduced him to PlaneMath™ and the "Applying Flying" activity where he could meet engineers who use math in their work. She wrote, "I wish you could have seen Jimmy's face when he realized that there were successful adults with physical limitations such as his . . . or worse. You would have cried! We have done much of the program together . . ." (Platano, 1999).

PlaneMath™ has received a number of awards and recommendations, including ED's A-OK Award from ED's Oasis; a selected resource of *The Scout Report*; one of the Web Crawler Select; a "Blue Web'N" from Pacific Bell Knowledge Network; and is an *Education World* reviewed site. Over 800 classrooms, with over 1,000 students with disabilities, have registered with the PlaneMath™ site. Because of the importance of context and relevance for adult learners, PlaneMath™ is also useful for adult remedial math practice and for career exploration.

Conclusion

The Internet is becoming an essential communication, education and job search tool for people in the labor force. The Internet has the potential for reducing many barriers to information and communication including geographic barriers and is a resource for

finding work opportunities. The inability to speak, hear, see, or move is not a limitation in electronic communication. The Internet has the potential to provide access to information and foster communication. It is particularly relevant to individuals with disabilities and other groups who may have been underrepresented in or underserved by traditional information, communication and educational systems.

This article has described examples of new computer and Internet tools and resources for improving the math readiness of people with disabilities. More tools will emerge as our technology improves and as the use of computers and the Internet continues to expand. Vocational counselors and educators should encourage students with disabilities to use these tools to increase their math knowledge and to develop math and computer skills needed for jobs in the current work force.


Notes

1. The Office of Special Education and Rehabilitative Services identified 5,541,166 children with disabilities, from ages 6 through 21, served under the Individuals with Disabilities Education Act (IDEA) and Chapter 1 of the Elementary and Secondary Education Act. Of these, 69,492 are identified as children with orthopedic disabilities that may include manual limitations, inability to manipulate paper and pencil for manual calculations, or inability to manipulate a hand-held calculator (U.S. Department of Education, 2000).

2. For this article, the vocational rehabilitation population is defined as individuals entering a state's vocational rehabilitation agency program. The data on math and reading levels for this population, provided to the author by Research Triangle Institute (RTI), are unpublished data from the Rehabilitation Services Administration's *Longitudinal Study of the Vocational Rehabilitation Services Program*, which is being conducted by RTI. In the Winter 1999-2000 issue of *American Rehabilitation*, RTI and RSA reported on findings re-

garding demographics and employment outcomes for those consumers who obtained competitive employment as a result of VR services during the study data collection period.

3. MathPad™ was developed by InfoUse with funding from the National Institute on Child Health and Human Development, National Institutes of Health. MathPad™ is distributed by Intellitools, Incorporated.

4. PlaneMath™ was developed by InfoUse with funding from the National Aeronautics and Space Administration (NASA). The PlaneMath™ Site is currently maintained by California State Polytechnic University, Pomona (www.Planemath.com). 

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International Exchange: *A Valuable Step Towards Employability*

Mary Ann Curulla Higgins

Jessica Lorenz, a 21-year-old San Francisco State University student, was one of 13 participants in the Mobility International USA (MIUSA) 3-week International Exchange Program to Costa Rica during the summer of 1999. During her last days in Costa Rica, Jessica wrote an article about her first international experience. She shared the following with her fellow participants, with and without disabilities (Lorenz, 1999):

"The MIUSA motto is an appropriate way to sum up the trip--'Challenge Yourself and Change the World.'™ We pushed the envelope, as they say, and I don't know about anyone else, but I learned that my maximum capacity is a lot greater than I ever knew. We learned so much and were positively changed. I know none of us will ever be the same."

Ms. Lorenz is blind and is enrolled in California's vocational rehabilitation (VR) program working towards getting a multi-subject teaching credential with the goal of becoming an adapted physical education teacher.¹ In California, getting hired as a teacher often requires Spanish language skills, so Ms. Lorenz is also working towards a minor in Spanish. When she suggested the international exchange program as part of her vocational training, her VR counselor agreed that it would be an added asset to her education endeavors by increasing her Spanish skills and disability knowledge, both of which would ultimately make her more employable as a teacher. She was fortunate to have a VR counselor who understood the connection between this international experience and her future employability.

International exchange participation often leads to an advantage in seeking employment whether you have a disability or not. That is why Lynnae Rutledge, assistant administrator for planning and policy with the Oregon Vocational Rehabilitation Division, feels it is vital for young adults with disabilities to include international experience as part of their preparations to enter the increasingly global U.S. job market. "Even with the ADA, people with disabilities in this country still are not always considered equally for positions of employment. A job applicant with a disability who has international experience brings that much more to the table to support his or her qualifications for the job." When an employer may be concerned whether an applicant with a disability can meet the demands of the job but then learns that the individual successfully studied in Brazil for a year, those worries may just disappear. The ability to be successful in an academic or structured international program implies that the person has a certain ability to be flexible, culturally aware, creative, and motivated, to say the least; and, if individuals have high employment expectations for themselves, an international experience may be just what is needed to lift them to the next level closer to reaching that goal. Lynnae Rutledge and many other successful individuals with disabilities employed in influential positions have had international experience. A few of them are: Judith Heumann, former Assistant Secretary for the Department of Education's Office of Special Education and Rehabilitative Services; journalist John Hockenberry; Heather Harker, a Kellogg fellow and a graduate student in the public administration program at

the John F. Kennedy School of Government at Harvard University; Rich Spittler, director of the Bay Area Outdoor Recreation Program; and Jan Garret, executive director of the Berkeley Center for Independent Living.

Based on 20 years of international and disability experience, Mobility International USA has compiled the following list of benefits of participating in an international program—such as studying, volunteering, researching, working, or interning abroad—all of which add to an individual's employability. These benefits include:

- A more open and accepting attitude towards cultural and diversity issues;
- The experience of learning how to function in a new environment;
- The opportunity to develop or improve second language skills;
- An increased interest in local and global community involvement;
- Leadership skills;
- Self-confidence;
- Independent-thinking skills;
- Increased self-awareness and self-direction;
- Improved general job skills (i.e., interpersonal skills, flexibility, and adaptability);
- The opportunity to learn other cultural and world view perspectives; and
- The opportunity to achieve a goal and experience a sense of accomplishment.

Funding Options

If a person with a disability is pursuing a career in which international experience is vital, there are some options to consider for funding. An excellent source for up-to-date, free information is the National Clearinghouse on Disability and Exchange (see Resources at the end of this article).

Vocational Rehabilitation Funding

"There is no federal regulation that prohibits the funding of an international program as part of an individual's vocational rehabilitation plan," according to Mary Davis, rehabilitation program specialist at the U.S. Department of Education's Rehabilitation Services Administration (RSA), the federal agency that oversees the state-federal vocational rehabilitation (VR) program. "Each state has flexibility in the nature and scope of what activities they cover, but cost alone can never be the only reason to deny a particular program." She adds, however, "There does need to be a clear link between the international activity and the individual's vocational objective." It also should be clear that the experience is not available through participation in a domestic program. If a VR counselor agrees that the experience would be valuable and the VR department is supportive, it should be written into the vocational plan. Also, if VR has approved funding for adaptive equipment or an assistant such as a note-taker to meet the vocational goal, it may be possible to use those funds to provide the same service while abroad. Ms. Davis recommends that individuals should discuss international program participation with their VR counselors if they feel it would increase their employability because some states may have state level VR policies that apply.

Jessica worked closely with her VR counselor to get approval to use VR funds to participate in an international exchange program. "When my VR counselor and I wrote up my ed-

ucational/vocational plan in February 1999, I was in the process of applying for the MIUSA exchange program. I told her that I was planning to apply and asked if that would be something that the department would support. My counselor said yes, and it was written into my plan. She and I kept in phone contact while all of the funding issues were being resolved. She never stopped encouraging me the entire time. When I was contacted by MIUSA about my selection for the program, my VR counselor said that the department would sponsor me, and she faxed confirmation of such to MIUSA."

Mary Davis of RSA and Jessica's counselor both agree that individuals who feel an international experience is crucial to their future employability but are denied the opportunity to gain that experience as part of their VR plan should use their right to appeal through the Client Assistance Program. If an individual can present a strong case that the experience would make him or her more employable, it should be supported.

Supplemental Security Income Provision

If an individual with a disability receives Supplemental Security Income (SSI) benefits and has the opportunity to participate in an international exchange program, that person should apply to have benefits continue while he or she is abroad. There is a little used SSI provision that allows for the continuation of benefits while participating in an overseas educational program. The exact wording from the *Social Security Handbook* (1999) is:

"A student of any age may be eligible for SSI benefits while temporarily outside the U.S. for the purpose of conducting studies that are not available in the U.S., are sponsored by an educational institution in the U.S., and are designed to enhance the student's ability to engage in gainful employment. Such a student must

Another option available to SSI beneficiaries to proactively plan for international exchange is through the SSI work-incentives program.

have been eligible to receive an SSI benefit for the month preceding the first full month outside the U.S."

This is an exception to SSI's more well-known "30-day rule" that does not allow for the continuation of SSI benefits to a person who is outside the United States for more than 30 days. The "30-day rule" was amended through legislation introduced by Congressman Peter Stark of California in 1994 as part of the Social Security Independence and Program Improvements Act, which became effective January 1, 1995, and the provision quoted above was a result. Even though the requirements to qualify are rigid, this provision makes it possible for people with disabilities to

Mrs. Higgins is a certified therapeutic recreation specialist working as an independent consultant in Ohio; she is currently working on several international exchange and disability projects for Mobility International USA (MIUSA). She worked for 5 years with MIUSA as an international exchange program coordinator and manager of the National Clearinghouse on Disability and Exchange. Over the past 6 years, she has led delegations of individuals with and without disabilities to Russia, Germany, Costa Rica, and Japan and coordinated numerous programs for international delegations in Eugene, Oregon. She has presented sessions on international opportunities for people with disabilities at professional conferences nationally.

gain international experience that will increase their employability and, while abroad, to continue to receive SSI benefits.

Another option available to SSI beneficiaries to proactively plan for international exchange is through the SSI work incentives program. An individual with a disability receiving SSI benefits can work with his or her VR counselor to apply for a Plan for Achieving Self-Support (PASS), through which an individual can set aside income or resources that will be used to achieve a career goal. The income set-aside in a PASS will then not be included in determining the individual's continued eligibility for SSI benefits (The Study Group, Inc., 1998). If international experience is approved by the VR counselor as necessary to meet a person's career goal, that individual can set aside income to cover some of the expenses related to participating in the program. For example, Sam has the approved career goal of becoming a German language interpreter. VR may approve the funding to cover his tuition and books to study in Germany for a semester, and a PASS plan would allow him to set aside income from his part-time job to purchase the airline ticket.

Health Insurance

Regarding health insurance, Medicaid and Medicare are not usually transferable overseas. Private health insurance may expect an individual to pay for expenses abroad and then turn in claim forms to be reimbursed when he or she returns to the United States. Individuals should check with their international exchange organization and health insurance provider to find out

about coverage abroad and discuss with them carefully any needs for pre-existing conditions coverage.

Summary

It is critical that people with disabilities recognize the importance of international experience and, when possible, include it as part of their preparation for employment. Different funding options are available. State-level VR services may provide funding to individuals for whom an international experience is part of their approved vocational plan. The Social Security Administration supports people with disabilities in getting the experience they need to be employed—including international experience if certain requirements are met. However, individuals going abroad may need to make arrangements for their own health insurance as Medicare and Medicaid are not generally transferable to people overseas.

Free information on the numerous international exchange options for people with disabilities is available from Mobility International USA and the National Clearinghouse on Disability and Exchange (see Resources at right).



Note

1. Adapted Physical Education (APE) is good teaching which adapts (modifies) the curriculum, task and/or environment so that all students can fully participate in physical education. Federal law (PL 94-142, PL 101-476, PL 105-17) mandates that physical education be provided to students with disabilities (from PE Central Website -

Website for Health and Physical Educators, <http://pe.central.vt.edu>)

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Lorenz, J. (1999). *Tribute to MIUSA, Over the Rainbow*, Mobility International USA.

Resources

Mobility International USA
The National Clearinghouse on Disability and Exchange
PO Box 10767
Eugene, OR 97440
Voice/TTY: (541) 343-1284
Fax: (541) 343-6812
E-mail: clearinghouse@miusa.org
URL: <http://www.miusa.org>

Georgia Thrower
Social Security Administration
112 Altmeyer Building
6401 Security Boulevard
Baltimore, MD 21235
Voice: (410) 965-3987
Fax: (410) 965-9063
E-mail: georgia.thrower@ssa.gov
URL: <http://www.ssa.gov>

Changing the Term "Job Placement" to Reflect Choice

The term "job placement" has been utilized in rehabilitation counseling for decades to depict the process in which the counselor assists individuals with disabilities to obtain employment. Because the word "placement" denotes a directional relationship implying that the rehabilitation counselor or professional retains the power to put individuals with disabilities into employment settings, the author suggests that the usage of the term "job placement" should be modified. Alternate phrases are proposed to reflect that "job placement" requires active choice by individuals with disabilities and that the ultimate choice of working or not belongs to individuals with disabilities, no matter what jobs the counselor or rehabilitation professional may arrange for them.

Erin C. Martz, M.A., C.R.C.

Using "person first" language when referencing people with disabilities is accepted as a professional standard in rehabilitation, as evident in language of the *Code of Professional Ethics for Rehabilitation Counselors* (Roessler & Rubin, 1998) and in psychology, as evident from the publication guidelines (American Psychological Association, 1994). Yet, the rehabilitation profession continues to use the term "job placement" to describe the process in which the counselor or rehabilitation professional assists individuals with disabilities to obtain employment, as it has for decades (Bridges, 1946). Because "job placement" carries a negative, patronizing connotation for persons with disabilities (Greenwood, 1982) and denotes a directional relationship or a linear "from-to" concept that implies that the counselor retains the power over individuals with disabilities to put them into jobs, it is proposed that this term should be replaced by a more appropriate phrase.

This proposed change fundamentally parallels the "person-first" argument that an individual should be described as a person with a disability (Blaska 1993; Manus, 1975; Kailes, 1985; Wright, 1960). Just as the phrase "person with a disability" is a "psychologically sounder expression" (Wright, 1960, p. 7), an individual in the rehabilitation process also should be identified verbally as a person making a choice to accept a job and, consequently, as a person actively partaking in the employment process. The term "placement" denotes a passivity, depicting the individual as someone who is put into a job by the counselor or rehabilitation professional. Not only does "placement" imply that the professional has the power in the rehabilitation counseling relationship, but this directional term of "placement" does not reflect that in any job opportunity, an individual ac-

tively chooses to start to work, to continue to work, or not to work in that specific job.

Philosophy of Job Placement

"Placement" can be defined as "the constellation of rehabilitation services that relate to employment and integration into the workplace" (Vandergoot, Staniszewski, & Merlo, 1992, pp. 305-306). "Placement" is depicted as "the logical conclusion of the rehabilitation process" because "the end goal of the vocational rehabilitation process is the achievement of an occupational objective" (Roessler & Rubin, 1998, p. 157). The techniques used by rehabilitation professionals to assist with the integration of individuals with disabilities into the workforce and with the achievement of an occupational and/or career objective have evolved and expanded over the decades. The focus of this section is not on the range of methods available to achieve employment; nor is it on the term used to describe the rehabilitation professional or counselor who is helping the client with employment issues. Instead, the philosophies underlying the methods of "job placement" will be briefly reviewed, in order to further emphasize the need to identify this important function in a more positive way, which would more accurately describe the active role played by the consumer in his vocational rehabilitation.

The benefits of two types of job placement philosophies have been debated since the 1970's (Vandergoot et al., 1992). The philosophy of the "counselor-centered placement" model can be described as a view that "clients require counselor intervention in the community to successfully secure and retain employment," due to its philosophy of person-job matching in which the rehabilitation professional assesses both the individual and the work environment (Salomone, 1996, p. 399). Examples of counselor-centered interventions include

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the broader categories of selective placement, transitional employment, supported employment, and the "placement" techniques of job development, negotiations with employers, arranging job coaches, and other advocacy measures that are deemed necessary for successful closure of the case (Salomone, 1996). As Vandergoot et al. noted (1992, p. 309), "Rehabilitation professionals now have more tools to change environments than ever before" with the explosion of technology that can be used to assist individuals with severe disabilities in the workplace.

While recognizing that individuals with more severe disabilities often need more counselor intervention in the community, Salomone (1996, p. 399) criticizes the philosophy of counselor-driven, person-job matching as "fostering dependency, rather than empowering people to claim (or reclaim) their lives." Further, Salomone (p. 405) argues that the counselor-centered techniques of "marketing" individuals with disabilities to employers, as if the individuals were "products," highlights the "absolutely fundamental" difference between counselor-centered and client-centered placement. The selective placement approach of counselor-centered rehabilitation counseling also can be described as more of a "directive approach," due to the necessity of assessing the person and the environment to facilitate good matches between people and jobs (Vandergoot, 1992, p. 308).

Client-centered placement has some similarities with counselor-centered placement, such as the continued support of the individual and expertise in the employment process proffered by the counselor. Yet, client-centered placement is depicted as a distinct philosophy that is based on a psycho-educational model of helping individuals discover their inner resources and their own abilities to obtain jobs (Salomone 1996). Thus, client-centered placement "seeks to empower clients to take charge of their own lives; to become their own best advocates and change-agents; to develop the requisite attitudes and skills to succeed in securing and maintaining; and then to adjust, adapt and ad-

vance in their careers" (Salomone, 1996, p. 410). In client-centered rehabilitation counseling, counselors act as "facilitators of client self-sufficiency and self-esteem; encouragers and supporters of client self-directed behaviors; teachers of skills for living in a complex society" (Salomone, 1996, p. 399).

Whether one chooses to agree with the philosophy of client-centered or counselor-centered placement is not essential for understanding the argument central to this article. Yet, knowledge of the distinct "placement" philosophies can serve to heighten the awareness of why "placement" is a term that should be replaced in the rehabilitation profession. Both of the client-centered and counselor-centered philosophies utilize the term "placement" with equivalent semantics. In both philosophies, the term "job placement" semantically suggests a linear concept of the counselor putting individuals with disabilities into jobs. To abbreviate Salomone's question (1996, p. 406), "What message is sent to people who are 'placed' . . . ?"

Individual Choice

The Americans with Disabilities Act, by its very name and its contents, acknowledges that individuals with disabilities are people first and should not be discriminated against because of their disabilities. Political support and awareness of "client choice" in the rehabilitation process is increasing, as reflected by the Rehabilitation Act Amendments of 1992 (Danek, Conyers et al., 1996). The acknowledgment of "client choice" is a "person-first" philosophy in disguise: "client choice" is a recognition that all individuals, no matter how severe their disabilities, are people first and foremost and therefore should be permitted to choose the path of their lives. The next step to reflect this awareness of individual choice would be to use a term that linguistically represents the concept that an individual makes a continuous choice in obtaining work (or not) while in the "placement" process.

Even though counselors or rehabilitation professionals may find job openings or negotiate with employers to cre-

ate positions for clients, clients still have the freedom of choice to refuse these positions. Hence, the term "placement" inappropriately suggests that the counselor puts a passive individual into a work position. Even if the individual does minimal work to obtain the job, the power of his or her freedom of active choice is preserved in the right to say "no" to that particular job. Granted the counselor or rehabilitation professional may have a greater understanding of the work world and what kind of vocational environment may best utilize the skills and abilities of the individual. But the term "job placement" does not reflect the fact that the individual continuously is choosing to work in any given situation, even if it is in an enclave or supported employment.

Though articles have been written addressing client choice in supported employment (Brooke, Wehman, Inge, & Parent, 1995; Dwyre & Trach, 1996; Everson & Reid, 1997; Olney and Salomone, 1992; West & Parent, 1992), a few professionals still may argue that some rehabilitation individuals truly must be "placed" into a supported employment position, due to their lower functioning levels, such as developmental disabilities or severe traumatic brain injuries. Obviously, the rehabilitation professional has had to invest time and energy in setting up and maintaining employment positions for these individuals.

However, because rehabilitation professionals are working with humans and not automatons, the individuals' choices to work or not to work must always be noticed and respected. Is an individual labeled as "acting out" on the job or vocational situation? Maybe the person is demonstrating such behaviors in order to send nonverbal messages about his or her choice to work or not to work in that job? Thus, even if individuals appear to have a very low awareness of their self-concepts, they can still express their choices by refusing to participate on the job. Consequently, freedom of choice in employment situations should be reflected on all levels of rehabilitation, including

those individuals with the most severe disabilities. To reflect this freedom of choice to work or not to work, it is necessary to replace the directional term "job placement" because it does not acknowledge the active agreement of the individual to work at a job, which may have been constructed for the individual by the counselor.

Alternate Terms

Greenwood (1982, p. 182) recognizes that "job placement" has a negative connotation that reflects a "paternalistic approach" and, accordingly, suggests that the term "job acquisition" could be used in its place. "Job acquisition" denotes an active process on the part of the individual, suggesting that the counselor or rehabilitation professional helps the individual with a disability to obtain a job. "Job acquisition" also has a positive connotation of gaining a job, in contrast to the implied passivity with the term "job placement" by its connotation of "being put" in a job.

Other terms may also be appropriate for the substitution of "job placement," such as a phrase containing the term "employment" (e.g., employment selection). With some creative thinking, the rehabilitation profession can update its biased terminology connected to the active process in which individuals with disabilities obtain and maintain employment.

Conclusion

"Job placement" is an umbrella term that can be used to depict many different ways of helping individuals with disabilities to find work. Because the semantics of the term "job placement" reflects a linear "from-to" concept symbolizing that the counselor or rehabilitation professional is the one with the power to put individuals with disabilities into jobs, it is proposed that other terms may be more appropriate to use in rehabilitation counseling. Manus (1975, p. 35) noted that "indirect expressions of attitudes toward disabled people can be inferred from our behavior, our speech and our language."

Hence, if the rehabilitation counseling relationship is to be depicted as an equal, balanced interaction between the counselor and individual, then it is advisable to examine why the biased term "job placement" is still being used in the rehabilitation profession.

In summary, the perspective that every single individual, no matter how severe his or her disability, ultimately chooses to work should be made evident in the terminology used in the rehabilitation profession. Therefore, the term "job placement" should be substituted with a term such as "job acquisition" or other possibilities, in order to reflect individual choice. Though this change may appear to be inconsequential to some people, it reflects a philosophical shift in a similar way that the change to using "person-first" language demonstrates a greater respect for the individual. By using terminology that represents a process of active individual choice, it will encourage an even greater respect of consumers' choice, whether they refuse or accept the vocational situations to which they have access.



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The Impact of Labor Market Trends on the Employment of Persons with Disabilities

Edward Yelin, Ph.D.

A number of changes have occurred in the labor market since 1960 and new trends have emerged that will influence employment in the United States in this new millennium. The extent to which the labor market experience of persons with disabilities reflects these trends are discussed in this article.

The changes in the labor market include: a *relative* shift from goods-producing occupations and industries to the distribution of services; the increasing demand for highly skilled and highly trained labor and the erosion of demand for those with less skill and training; the emergence of new ways of

accomplishing work within the firm; and the emergence of alternative work arrangements throughout the economy (Bell, 1983; Piore and Sabel, 1984; Hirschhorn, 1988; Levy, 1987; Wilson, 1997).

Some of these trends are relatively easy to quantify, such as the growth of jobs in the service sector. Some are more difficult to measure and evaluate, for example the growth of contingent employment arrangements (Belous, 1989; Polivka, 1996), the putative erosion of job security (Nardone, Veum, and Yates, 1997) and the flattening of workplace hierarchies (Osterman, 1988). Many analysts view the sum total of the changes as a dramatic shift in the workplace, and one that may affect profoundly the ability of persons

with disabilities to secure and retain employment.

Labor Market Dynamics: 1960 to the Present

Dynamics in Labor Force Participation. The 1950's and 1960's are viewed by some as the halcyon era in the U.S. economy, with high growth rates sustaining unprecedented increases in the standard of living and allowing most families to survive on one income, in turn reinforcing the social ethic of the time that women should not work outside the home (Levy, 1987). In 1960, just under 60 percent of the working-age population was in the labor force (Table 1). The overall labor force participation rate increased by more than 12 percent in the interim, having reached almost two-thirds as of 1996.

Gender. This overall increase in labor force participation rates masks substantial differences in participation by gender and age (Table 1). Among all working-age men, labor force participation rates declined by more than 10 percent, but men 55 to 64 experienced an even steeper decline, 22.8 percent. Conversely, among all working-age women, labor force participation rates rose by 57.3 percent, from 37.7 percent in 1960 to 59.3 percent in 1996. Among women 25 to 34, labor force participation rates more than doubled, from 36.0 percent in 1960 to 75.2 percent in 1996. Thus, the overall increase in labor force participation rates represents the net effect of a decline among men, particularly older men, and an increase among women, particularly younger women.

Table 1

Labor Force Participation Rates,
by Gender and Age, United States, 1960-1996

Group	1960 %	1970 %	1980 %	1990 %	1996 %	% Change
All Persons	59.4	60.4	63.8	66.5	66.8	12.5
Men, 18-64	83.3	79.7	77.4	76.4	74.9	-10.1
55-64	86.8	83.0	72.3	67.8	67.0	-22.8
Women, 18-64	37.7	43.3	51.6	57.5	59.3	57.3
25-34	36.0	45.0	65.4	73.5	75.2	108.9

Sources: Statistical Abstract of the United States, 1981, pg. 381;
Statistical Abstract of the United States, 1997, pg. 397.

Race. Race plays a part in labor market dynamics and would appear to interact with gender.¹ In the last quarter century, labor force participation rates increased among all working-age whites by 11.5 percent, but the increase among all working-age African Americans was only 3.7 percent (Table 2). The decrease in labor force participation rates among all working-age white men was only about half that experienced by African American men (5.3 vs. 10.2 percent, respectively), while the increase among white women was far larger than that among African American women (38.7 vs. 22.0 percent, respectively). In 1970, African American men were almost as likely as white men to be in the labor force, but this was no longer the case in 1996. In 1970, African American women had significantly higher labor force participation rates than white women. After the larger increase in labor force participation rates among white women since 1970, the two groups of women have nearly identical labor force participation rates.

Age. Another factor affecting the labor market over the last several decades—and likely to have an even more profound impact on the proportion of the working-age population at risk for work disability in the years to come—has been the dramatic change in the age structure of society as the baby boomers grow old (Table 3). Thus, the proportion of the population 18 to 34 years of age rose substantially between 1960 and 1980, but has since fallen, while the proportion 35 to 44 rose between 1980 and 1996, and the proportion 45 to 54 has just now begun a precipitous increase, to be followed in the decade to come by a substantial rise in the proportion of workers 55 and over.

The significance of age in the labor market can be seen in Table 4, which shows labor force participation rates by age. In 1996, more than 80 percent of persons in each of these age groups—20 to 34, 35 to 44, and 45 to 54—were in the labor force. In each case, these percentages had risen over time as the labor market accommodated the sub-

Table 2

**Labor Force Participation Rates,
by Race and Gender, United States, 1970-1996**

Group	1970 %	1980 %	1990 %	1996 %	% Change
Whites	60.2	64.1	66.9	67.1	11.5
Men	80.0	78.2	77.1	75.8	-5.3
Women	42.6	51.2	57.4	59.1	38.7
African Americans	61.8	61.0	64.0	64.1	3.7
Men	76.5	70.3	71.0	68.7	-10.2
Women	49.5	53.1	58.3	60.4	22.0

Sources: Statistical Abstract of the United States, 1991, pg. 407;
Statistical Abstract of the United States, 1997, pg. 397.

Table 3

Age Structure of U.S. Population, 1960-1996

Age	1960 %	1970 %	1980 %	1990 %	1996 %
18-34	21.6	24.4	29.6	28.2	23.2
35-44	13.4	11.3	11.3	15.1	16.4
45-54	11.4	11.4	10.6	10.1	12.2
55-64	8.6	9.1	9.6	8.5	8.1
65 or older	9.2	9.8	11.3	12.5	12.8

Sources: Statistical Abstract of the United States, 1984, pg. 31;
Statistical Abstract of the United States, 1997, pg. 15.

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stantial increase in labor force participation rates among women. The increase in the labor force participation rates of young and middle-aged workers can also be attributed to the baby boomers. From 1960 to 1996, the labor market accommodated an increasing percentage of a substantially larger number of persons.

However, labor force participation rates are much lower among persons 55 to 64 than among those 45 to 54, and declined among persons in the 55 to 64 and the 65 and older age groups throughout most of the last two decades. The decrease in labor force participation rates among persons 55 to 64 before 1990 occurred because more people these ages chose to leave work prior to the ages when Social Security eligibility begins (62) and reaches its maximum (currently 65). Labor force participation rates are lower among persons 55 to 64 at any one point because persons these ages face higher rates of displacement from their jobs and because the prevalence of health problems associated with aging begin to affect a substantial number of people at these ages. As a result of the increased number of persons who are 55 to 64, a higher proportion of the working-age population will be at risk for the onset of the chronic diseases of the aged, which may reduce the overall labor force participation rate.

Education. As was seen in Table 1, above, the proportion of working-age adults in the labor force rose substantially between 1970 and 1996. The increase in labor force participation rates affected all but those individuals who have not finished high school (Table 5). Moreover, the magnitude of the increase was larger with each increment in education. Thus, labor force participation rates increased among high school graduates by 11.0 percent, among those with some college by 13.4 percent, and among those with a college degree or more, by 19.0 percent. As a result, by 1996, the labor force participation rate among college graduates was almost 50 percent higher than among persons with less than a high school education.

Table 4

Labor Force Participation Rates, by Age, United States, 1960-1996

Age	1960 %	1970 %	1980 %	1990 %	1996 %
20-34	62.0	65.0	77.3	81.4	81.6
35-44	67.3	65.0	79.7	85.7	84.3
45-54	72.1	73.3	74.1	80.9	81.5
55-64	56.4	60.3	55.2	54.8	57.1
65 or older	19.2	16.1	12.1	10.9	11.8

Sources: Author's calculations based on information in:
 Statistical Abstract of the United States, 1984, pg. 31;
 Statistical Abstract of the United States, 1990, pg. 13;
 Statistical Abstract of the United States, 1997, pg. 15, 400

Table 5

Labor Force Participation Rates, by Education Attainment, United States, 1970-1996

	1970 %	1980 %	1990 %	1996 %	% Change
Less than High School	65.5	60.7	60.7	60.2	-8.1
High School Graduate	70.2	74.2	78.2	77.9	11.0
Some College	73.8	79.5	83.7	83.7	13.4
College Grad or More	73.8	86.1	87.8	87.8	19.0
Gradient	1.13	1.42	1.45	1.46	

Source: Statistical Abstract of the United States, 1997, pg. 399;

Since 1960, the proportion of the adult population with at least a high school degree has almost doubled . . . and the proportion with 4 or more years of college has more than tripled

Since 1960, the proportion of the adult population with at least a high school degree has almost doubled (from 41.1 to 81.7 percent), and the proportion with 4 or more years of college has more than tripled (from 7.7 to 23.6 percent) (U.S. Bureau of the Census, 1997, 159). Nevertheless, a substantial fraction of the cohorts entering the ages of highest risk for work disability have less than a high school education, including more than 12 percent of those now 35 to 44, more than 13 percent of those now 45 to 54, and more than 22 percent of those now 55 to 64 (ibid, 160). These individuals may face a difficult time maintaining a toehold in the labor market. In addition, about a third of these cohorts have no more than a high school degree. Although the labor force participation rate for high school graduates increased by 11.0 percent overall since 1970, it decreased slightly between 1990 and 1996. If this trend were to continue or accelerate, the number of persons at jeopardy in the labor market would include some of these individuals.

Dynamics in Employment Characteristics. There is little doubt that there has been a fundamental shift in the *kind* of work done, as reflected in the change in the distribution of occupations and industries. However, analysts disagree on the degree to which there has been a corresponding shift in how work is done. Osterman (1988) noted that throughout much of this century, firms had two kinds of employees: a salaried workforce paid to design and monitor work processes and given relative au-

Table 6						
Number of Employees (in millions) and Shares of Non-Agricultural Employment, by Industry, United States, 1960-1996						
Industry	1960	1970	1980	1990	1996	% Change in Shares
Mining and Construction	3.6 (6.7%)	4.2 (6.0%)	5.4 (5.9%)	5.8 (5.3%)	6.0 (5.0%)	-25.4
Manufacturing	16.8 (31.0%)	19.4 (27.3%)	20.3 (22.4%)	19.1 (17.4%)	18.2 (15.3%)	-50.7
Transportation, Utilities, and Communications	4.0 (7.4%)	4.5 (6.4%)	5.2 (5.7%)	5.8 (5.3%)	6.4 (5.3%)	-28.4
Wholesale/Retail Trade	11.4 (21.0%)	15.0 (21.3%)	20.3 (22.5%)	25.8 (23.5%)	28.2 (23.6%)	12.4
Finance, Insurance, and Real Estate	2.6 (4.9%)	3.7 (5.1%)	5.2 (5.7%)	6.7 (6.1%)	7.0 (5.8%)	18.4
Services	7.4 (13.6%)	11.6 (16.3%)	17.9 (19.8%)	27.9 (25.5%)	34.4 (28.7%)	111.0
Public Administration	8.4 (15.4%)	12.6 (17.7%)	16.2 (18.0%)	18.3 (16.7%)	19.5 (16.3%)	5.8*

* Percent change for 1996 vs. 1980 period=-9.4%

Sources: Statistical Abstract of the United States, 1981, pg. 394;
Statistical Abstract of the United States, 1997, pp. 415, 422.

tonomy to carry out their work and security of employment (the term "white collar" may be applied to such workers); and an hourly wage work force to implement these work processes, given little discretion over how work was carried out, and retained only when the demand for the products justified continued employment (traditionally called "blue collar" workers). Osterman observed that, more recently, many firms were melding the two kinds of jobs: bringing the expertise of those involved in the production of goods and services into the design of work processes, while reducing the security of employment among the white collar workforce.

The signposts for the changes described by Osterman include flattened workplace hierarchies, broadened and variable work tasks for each job, reduced job tenure, increased use of part-time and temporary workers, alterna-

tive work arrangements, and higher rates of job displacement.

Industries. Table 6, which shows the change in the number of employees and share of non-agricultural employment among industries since 1960, provides information on the most tangible signpost of the change in the nature of work. In 1960, the goods producing sectors of the economy—mining and construction and manufacturing—accounted for 6.7 percent and 31.0 percent of employment, respectively. Since then, the share of employment accounted for by mining and construction has decreased by about a quarter, and the share accounted for by manufacturing by slightly more than half. Indeed, at a time when total employment more than doubled (datum not in table), the absolute number of manufacturing workers increased by only 8 percent, from 16.8 million in 1960 to 18.2 million in 1996. Thus, as of

Table 7

Number of Employees (in millions) and Shares of Non-Agricultural Employment in Various Service Industries, United States, 1970-1996

Service Industry	1970	1980	1990	1996	% Change in Shares
Business and Repair	1.4 (1.9%)	3.9 (4.0%)	7.5 (6.5%)	8.1 (6.6%)	247.4
Personal	4.3 (5.7%)	3.8 (4.0%)	4.7 (4.1%)	4.4 (3.5%)	-38.6
Entertainment and Recreation	0.7 (1.0%)	1.1 (1.1%)	1.5 (1.3%)	2.4 (1.9%)	90.0
Professional	12.9 (17.2%)	19.9 (20.7%)	25.4 (21.9%)	30.1 (24.4%)	41.9

Source: Statistical Abstract of the United States, 1997, pg. 415.

1996, the goods producing sectors of the economy accounted for only a fifth of total employment.

Concurrently, there was substantial growth in the share of employment accounted for by the finance, insurance and real estate sectors (18.4 percent, net of the decline from 1990 to 1996) and by the service industry (111.0 percent). Primarily as a result of growth occurring prior to 1980, the share of total employment accounted for by the public administration sector increased by 5.8 percent; since 1980, however, its share has declined by 9.4 percent.

Because the service sector is heterogeneous, encompassing the physician's office as well as those who work in private households and engineering firms as well as home cleaning services, it is far more informative to study the employment dynamics within the components of the overall services category. The share of employment in all but the personal services component expanded between 1970 and 1996, with business and repair, entertainment and recreation, and professional services growing by 247.4, 90.0, and 41.9 percent, respectively (Table 7). By 1990, the absolute number of workers in professional services

Absolute growth in the number of professional and managerial workers continues apace

exceeded 30 million, almost a quarter of all non-farm employment. Within the business and repair services component, the absolute number of workers in personnel supply firms (including temporary employment agencies) increased more than fivefold between 1970 and 1996, while the number in the computer and data processing services fields increased more than fourfold (data on absolute number of workers in these specific industries are not in the table).

Occupations. The change in the share of employment among occupations reflects the shift in the overall economy from the production of goods to the production and distribution of services (Table 8). Thus, the share of employees in professional specialty and managerial occupations; technical, sales, and administrative workers; and service workers increased by 30.3, 39.4 and 11.5 percent, respectively, while the share in precision production and

craft occupations; operatives, fabricators and non-farm laborer; and farming and fishing occupations decreased by 17.7, 39.0 and 64.0 percent, respectively.

The shift from manufacturing to service occupations does not necessarily mean an absolute reduction in the former. Indeed, in absolute terms, the number of precision production and craft workers, and operatives, fabricators and non-farm laborers is *substantially greater* now than in 1960, and has been relatively stable since 1980. Among major occupational classifications, only farming and fishing occupations have declined in absolute terms throughout the period covered. In contrast, the absolute number of persons in professional and managerial and technical, sales and administrative occupations has more than doubled (from under 14.6 to 36.5 million in the former and from 14.0 to 37.7 million in the latter), and the number of service workers has increased twofold (from 8.0 to 17.2 million). Absolute growth in the number of professional and managerial workers continues apace, but it would appear that growth is abating among technical, sales and administrative and service workers (the number

Table 8

**Number of Employees (in millions) and Shares of Employment, by Occupation,
United States, 1960-1996**

Occupation	1960	1970	1980	1990	1996	% Change in Shares
Professional Specialty and Managerial Occupations	14.6 (22.1%)	19.4 (24.7%)	26.5 (27.3%)	30.6 (25.8%)	36.5 (28.8%)	30.3
Technical, Sales, and Adm. Workers	14.0 (21.3%)	18.6 (23.6%)	24.3 (25.0%)	36.9 (31.1%)	37.7 (29.7%)	39.4
Service Workers	8.0 (12.2%)	9.7 (12.4%)	13.0 (13.3%)	16.0 (13.5%)	17.2 (13.6%)	11.5
Precision Production and Craft Workers	8.6 (13.0)	10.2 (12.9%)	12.5 (12.9%)	13.7 (11.6%)	13.6 (10.7%)	-17.7
Operatives, Fabricators, and Non-Farm Laborers	15.6 (23.6%)	17.6 (22.4%)	18.4 (18.9%)	18.2 (15.2%)	18.2 (14.4%)	-39.0
Farming and Fishing Occupations	5.2 (7.8%)	3.3 (4.0%)	2.7 (2.8%)	3.5 (2.9%)	3.6 (2.8%)	-64.0

Sources: Statistical Abstract of the United States, 1981, pg. 401;
Statistical Abstract of the United States, 1997, pp. 410-412;
and calculations from U.S. Department of Labor, Bureau of Labor Statistics web Site.

of workers in the former category increased by less than a million between 1990 and 1996, while the number in the latter increased by just more than a million during this time). The continued growth in professional and managerial occupations, with relative stasis among technical, sales and administrative and service workers, belies the prediction that the American economy would be producing few good jobs and many bad ones (Braverman, 1974; Wright and Singleman, 1982).

Part-Time Employment. The proportion of the employed population working part time has increased steadily since 1970, from 13.2 to 17.4 percent (Table 9). The Bureau of Labor Statistics (BLS) divides part-time employment into voluntary and involuntary components (labeled "non-economic" and "economic" reasons, respectively). Overall, the proportion of all employment that is part-time due to economic reasons increased from 2.8 to 3.4 percent between 1970 and 1996, or by more

Table 9

**Part-Time Work for Economic, Non-Economic, and All Reasons
Among Employed Persons, United States, 1970-1996**

Reason	1970 %	1980 %	1990 %	1996 %	% Change
Economic*	2.8	4.1	4.3	3.4	21.4
Non-Economic**	10.4	11.0	12.9	14.0	34.6
All	13.2	15.1	17.2	17.4	31.8

* Also called "involuntary" reason.

** Also called "voluntary" reason.

Sources: U.S. Department of Labor 1985, pp. 6-7;
U.S. Department of Labor 1988, pp. 710-712.;
U.S. Bureau of the Census 1990, pg. 380; and calculations using information from:
U.S. Department of Labor, Bureau of Labor Statistics Web site.

than 20 percent in relative terms. However, the proportion working part-time for economic reasons has actually decreased from the 4.3 percent level in 1990 due to the improvement in the labor market. In contrast, the proportion working part-time for non-economic reasons increased steadily and grew overall by more than a third since 1970, from 10.4 to 14.0 percent of the employed population.

Terms of Employment. It is frequently claimed that an increasing fraction of all work is not in the traditional mode of being permanent, reasonably secure, in the direct employ of the firm in which the work is done, and with the work done at a worksite maintained by the firm. The Bureau of Labor Statistics has kept abreast of many of the changes in the terms of employment in its data collection efforts, but time-trends are not available for all of them.

Job security is measured by length of time on the job (tenure) and having the expectation of staying on the same job for an additional year (contingency) (Nardone, Veum, & Yates, 1997). With respect to job tenure among men, the overall median has not changed much since the early 1980's. However, this is because the male workforce has aged and older workers have longer tenures. Within each age range, job tenure among men has decreased. Among women, job tenure has increased both because the fraction in older age groups has increased and because tenure for women 35 to 44 and 45 to 55 has increased (U.S. Department of Labor, Bureau of Labor Statistics, 1997). Thus, the picture for job tenure is a mixed one, with women having unambiguously longer tenures, men having shorter tenures at each age and more men than women being in the ages with longer tenures.

The Bureau of Labor Statistics defines contingent employment three ways: as the proportion of wage and salary workers whose jobs have lasted a year or more but who do not expect it to last another year; the proportion of such workers as well as the self-employed and independent contractors in this situation; and the proportion of

both who do not expect their jobs to last another year regardless of how long they have been at those jobs. The proportion meeting each definition declined slightly between 1995 and 1997: for the first definition, from 2.2 to 1.9 percent of all workers; for the second, from 2.8 to 2.4 percent; and for the third, from 4.9 to 4.4 percent (U.S. Department of Labor, Bureau of Labor Statistics, 1997a). Thus, contingency is reasonably common, but has definitely not increased in the last few years. It should be re-emphasized, however, that the recent decline may be due to the strength of the labor market in the last few years, and not be representative of a long-term trend in security of employment.

Alternative work arrangements include the use of independent contractors, on-call workers, workers provided by temporary help agencies, and workers provided by contract firms. The Bureau of Labor Statistics has collected information on such arrangements only twice, in 1995 and 1997. The proportion of the employed with alternative work arrangements did not change substantially during this 2-year period. As of 1997, 6.7 percent of all workers were independent contractors, 1.6 percent were on-call workers, 1.0 percent worked for temporary help agencies, and 0.6 percent were workers provided by contract firms.

Flexible work arrangements involve the shift from the direct hiring of workers to perform certain functions to the purchase of the services of other firms for those functions. There is no way to be sure that there has been a net expansion in the procurement of services outside the firm because firms may be hiring for new functions while procuring services formerly done within the firm. Instead, the Bureau of Labor Statistics collects information on the proxy measures of the magnitude of employment in industries and occupations that are felt to represent services that could be done outside a firm (Clinton, 1997). Using such measures, it would appear that there has been substantial growth in procurement from outside of firms. The share of total employment in the business services sector has increased

threefold since 1972 and one component of this industry-personnel supply—has increased more than sevenfold during this time. In addition, there has been substantial growth in the engineering and management consulting sectors. There is another piece of evidence consistent with the notion that certain functions are being performed by workers not directly hired by firms: firms in a majority of industries have reduced their employment of business support occupations, those that are most likely to be performed by outside contractors.

Change in location of work, from the workplace to home. The Bureau of Labor Statistics has collected information twice on the number of persons who do at least part of their jobs from home, in 1991 and 1997 (U.S. Department of Labor, Bureau of Labor Statistics, 1998). The number of persons who do some work at home was slightly more than 21 million (17.8 percent of the workforce) in 1997 and has not increased substantially since 1991. However, an increasing fraction of persons who work at home are paid to do so. Almost two-thirds of persons who work at home are in managerial and professional specialty occupations.

Change in the Internal Structure of Work. The workplace literature suggests a trend toward diffusing authority over decisions about the way work is done throughout the hierarchy, toward increasing use of flexible work groups that coalesce only for the duration of specific projects and toward increasing the mix of tasks done by the individual

Firms in a majority of industries have reduced their employment of business support occupations, those that are most likely to be performed by outside contractors.

(Cornfield D, 1987; Osterman, 1988; Kelley, 1990; Hirschhorn, 1991). The evidence for this kind of shift derives from qualitative studies of the shop floor and office and from interviews and case studies of managers and line workers. However, without statistical evidence that such changes are widespread, it is difficult to ascertain what proportion of the workforce has experienced them. In the 1970's, the Department of Labor collected this kind of data in the *Quality of Employment* surveys; it has not been collected since (Quinn and Staines, 1979; Schwartz, Pieper & Karasek, 1988).

The potential importance of changes in the internal organization of work for persons with disabilities is profound. Flexibility in the pace and schedule of work and autonomy in how work is done have been shown to be strongly correlated with whether or not someone is able to maintain employment (Yelin, et al., 1980). Thus, if the observation that these conditions are more prevalent in work now than in the past were to be true, it might augur an improvement in the employment picture for persons with disabilities. On the other hand, for persons with cognitive, communications and psychological disabilities, the need to interact with a constantly changing array of workgroups and the impermanent working conditions may make it more difficult to work. Although it would be hard to capture these qualitative changes in working conditions in large-scale labor market surveys, they may be more important in determining the employment prospects of persons with disabilities than the more objective changes in employment described above.

Rates of Displacement. The Bureau of Labor Statistics defines job displacement as the loss of a job held on a long-term basis (3 or more years). The BLS has tracked job displacement since the early 1980's (Hipple, 1997). The overall rate of job displacement seems tied to the economic cycle and, thus, rose with the recession in the early 1980's, fell with the recovery late in that decade, rose once again with the recession early in this decade, and has since fallen. However, the composition of displaced

Table 10

Labor Force Participation Rates of Persons with and without Disabilities, by Gender, United States, 1983-1994

Group	1983 %	1994 %	% Change
All Persons	75.0	78.4	4.8
with disabilities	48.6	51.8	6.6
without disabilities	79.1	83.0	4.9
All Men	87.2	86.9	-0.3
with disabilities	60.0	58.8	-2.0
without disabilities	91.5	91.4	-0.1
All Women	63.8	70.6	10.7
with disabilities	38.0	45.6	20.0
without disabilities	67.6	74.9	10.8

Source: Adapted from Trupin, et al., 1997.

Table 11

Labor Force Participation Rate of Persons with and without Disabilities, by Educational Attainment, with Adjustment for Health and Functional Status and Demographic Characteristics, United States, 1995

	% Persons with Disabilities	% Persons without Disabilities
Less Than High School	12.4	67.7
High School	23.9	80.3
Some College	33.5	80.0
College Graduate	41.6	86.7
Some Graduate School or More	47.5	88.0

Source: Author's analysis of 1995 *Current Population Survey*

workers has changed considerably. In the early years of the BLS data collection efforts, the rate of displacement was much greater in manufacturing industries and in the occupations such as craft workers and operatives that were concentrated in those industries. In the interim, the rate of displacement has grown faster in white collar occupations (and is now almost as large in such occupations as in blue collar ones) and has even begun to spread to rapidly expanding industries, such as the finance, insurance and real estate sectors. Thus, although a large proportion of displacement is due to cyclical changes in the economy, it would appear that a portion of job displacement occurs in successful and expanding sectors. Job displacement is becoming a more generalized strategy of accommodating change in the labor force and is not limited to select occupations and industries facing difficult times.

The Labor Market and Persons with Disabilities

Persons with disabilities have experienced most of the major trends in the labor market over the last several decades, albeit in exaggerated form. In this section, I review the evidence to support this statement. The data on time-trends among persons with disabilities, however, do not cover the same periods as the general labor market data reviewed in the prior section because most federal data series do not collect information on disability status with the same regularity as for characteristics as gender, race and age.

Labor Force Participation Rates. Between 1983 and 1994, labor force participation rates among all working-age persons increased by 4.8 percent

Persons with disabilities more than shared in the overall increase in the proportion of working-age adults actually in the labor force.

Table 12			
Shares of Employment of Persons with and without Disabilities, by Industry, United States, 1995			
Industry	% With Disabilities	% Without Disabilities	Ratio
Mining and Construction	9.5	9.5	1.00
Manufacturing	14.1	16.6	.85
Transp., Utilities and Communications	6.4	6.8	.94
Wholesale/Retail Trade	21.7	20.6	.97
Finance, Insurance and Real Estate	3.9	6.3	.62
Services	39.2	34.8	1.13
Business and Repair	9.9	5.9	1.68
Personal	4.9	3.4	1.44
Entertainment and Recreation	1.7	1.7	1.00
Professional	22.7	23.8	.95
Public Administration	5.3	5.5	.96

Source: Author's analysis of 1995 Current Population Survey.

(Table 10). Although persons with disabilities continued to have lower labor force participation rates than persons without disabilities in 1994 (51.8 percent and 83.0 percent, respectively), such persons experienced a larger relative increase (6.6 percent) than those without (4.9 percent). Thus, persons with disabilities more than shared in the overall increase in the proportion of working-age adults actually in the labor force.

Gender, Age, and Race. Persons with disabilities also experienced trends in labor force participation by gender to a heightened degree. Thus, while labor force participation rates were increasing 10.8 percent among women without disabilities between 1983 and 1994, women with disabilities experienced an increase of almost twice the magnitude during this time (20.0 percent). Concurrently, men with disabilities experienced a larger decline in labor force participation rates

than men without (-2.0 and. -0.1 percent, respectively).

Recall from Tables 2 and 3, above, that the decline in labor force participation rates among men was concentrated among men 55 to 64 and/or among non-white men, particularly such men who are in this age range, and that the increase in labor force participation rates among women was concentrated among women 25 to 34, especially white women who are in this age range. Persons with disabilities experienced each of these trends in a heightened form (Yelin, 1994). Thus, labor force participation rates among men 55 to 64 with disabilities declined to a greater degree than among such men without disabilities, and non-white men these ages with disabilities experienced the largest relative decline in labor force participation of any single group defined by gender, age, race, and disability status. In contrast, young women with disabilities, particularly young white women with disabilities, experienced the largest increase of any single group defined by these four characteristics.

Education. Persons with disabilities are overrepresented among persons with a high school education or less and underrepresented among those with some college or more (data from author's analysis of 1995 *Current Population Survey*). However, at every level of education, they have lower labor force participation rates than persons without disabilities, even after statistical adjustment for differences in health and functional status and demographic characteristics (Table 11). The difference in labor force participation rates is greater at lower levels of education. For example, the labor force participation rate among persons with disabilities with less than a high school education is about a fifth as great as among such persons without disabilities (12.4 and 67.7 percent, respectively), but persons with disabilities who have some graduate school or more have a labor force participation rate more than half that of persons without disabilities (47.5 and 88.0 percent, respectively). Attaining higher

Table 13			
Shares of Employment of Persons with and without Disabilities, by Occupation, United States, 1995			
Occupation	% With Disabilities	% Without Disabilities	Ratio
Professional Specialty and Managerial Occupations	15.7	27.5	.57
Technical, Sales, and Administrative Workers	28.8	30.0	.96
Service Workers	20.3	13.6	1.49
Precision Production and Craft Workers	10.8	11.0	.98
Operatives, Fabricators, and Non-Farm Laborers	20.3	14.7	1.38
Farming and Fishing Occupations	3.0	2.6	1.15
Armed Forces	0.3	0.7	.43

Source: Author's analysis of 1995 *Current Population Survey*.

levels of education improves the employment prospects of persons with disabilities to a greater degree than for persons without disabilities, but even when persons with disabilities have gone to graduate school, they still do not achieve as large a return on education as persons without disabilities. Overall, persons with disabilities experience low labor force participation rates both because they have low levels of education and lower returns from every level of education.

Employment Characteristics and Persons with Disabilities. Given employment, do persons with disabilities have access to the same mix of jobs and to the same working conditions as those without disabilities?

Industries. Table 6 shows that three industrial sectors have had a declining share of employment (*mining and construction, manufacturing and transportation, utilities and communications*), three have had a substantially increasing

share (*wholesale/retail trade, finance, insurance and real estate and services*), and one has had little change, net of an increase prior to 1980 and a decline since then (*public administration*). Table 12 shows the mix of industries in 1995 among persons with and without disabilities who were employed. There are no clear patterns: Persons with disabilities are underrepresented among two sectors with a declining share of employment (*manufacturing and transportation, utilities and communications*) and one with an increasing share (*finance, insurance and real estate*), while having a larger share of overall employment in service industry and in two of the components of this sector (*business and repair and personal services*). Persons with disabilities have a smaller share of employment in *professional services*—the largest service industry component—than persons without disabilities.

Occupations. The occupations with an increased share of employment over the last several decades include *professional specialty and managerial occupations, technical, sales and administrative workers and service workers*, while *precision production and craft workers, operatives, fabricators and non-farm laborers, and farming and fishing occupations* have had declining shares of employment. With respect to the occupations with an increased share of employment, persons with disabilities are much less likely than those without to be in *professional specialty and managerial occupations*, they are about as likely to be in *technical, sales and administrative occupations*, and they are more likely to be *service workers* (Table 13). With respect to the occupations with a declining share of employment, persons with and without disabilities are equally likely to be *craft workers*, but persons with disabilities are much more likely to be *operatives* and to be in *farming and fishing occupations*.

Part-Time Employment. Persons with disabilities have experienced a disproportionate amount of the increase in part-time employment (Table 14). As of 1995, 36.8 percent of persons with disabilities reported that their employment was part-time, an increase of 31.9 percent since 1981. The increase in part-time employment among persons without disabilities—1.8 percent—was far smaller. Among persons with disabilities, the prevalence of part-time work due to economic reasons rose at least until the early 1990s, but has since fallen. Among persons without disabilities, it has fallen steadily since the mid-1980s. Over the entire period under study, persons with disabilities have experienced a much smaller decline in part-time employment for economic reasons than persons without disabilities—1.6 vs. 11.6 percent.

Persons with disabilities have experienced a substantial increase in part-time employment for non-economic reasons during this decade, leading to an overall increase of 41.7 percent in this measure over the entire period under study. In contrast, the rate of

Table 14					
Part-Time Work for Economic, Non-Economic, and All Reasons Among Employed Persons with and Without Disabilities, United States, 1980-1995					
Reason	1981 %	1985 %	1990 %	1995 %	% Change
Economic					
Persons with Disabilities	6.3	7.9	9.1	6.2	-1.6
Persons without Disabilities	4.3	5.2	4.1	3.8	-11.6
Non-Economic					
Persons with Disabilities	21.6	20.3	24.7	30.6	41.7
Persons without Disabilities	12.4	11.9	12.4	13.2	6.5
All					
Persons with Disabilities	27.9	28.2	33.8	36.8	31.9
Persons without Disabilities	16.7	17.1	16.5	17.0	1.8

Source: Author's analysis of Current Population Survey, 1981-1995.

part-time employment for non-economic reasons has not changed much among those without disabilities in this decade and has risen by only 6.5 percent since 1981.

Terms of Employment. Of the measures of the terms of employment reviewed with respect to the entire labor force, above, none is available on an ongoing basis from the *Monthly Current Population Survey* or the *Annual March Supplement to the Current Population Survey*, the major source of data on employment in the United States. Instead, the measures—tenure, contingency, flexibility, alternative work arrangements, and work at home—are not collected routinely and, when collected, they are part of infrequent surveys in which respondents are not asked to report

disability status. Because of the lack of consistent data on terms of employment among persons with and without disabilities from the Bureau of Labor Statistics surveys, one is forced to use the results of less comprehensive surveys. In one such survey, a random sample of California working-age adults was interviewed in 1996 about working conditions and current employment status. The results indicate that persons with disabilities were more likely to have temporary employment. Paradoxically, they reported longer job tenure, even after adjustment for age and gender. It is possible that they may be locked into jobs because of their disability and the attendant need to maintain benefits, especially employer-provided

health insurance. Persons with disabilities were no more likely to work at home, the only measure of work arrangement available in the survey. Finally, compared to persons without disabilities, persons with disabilities were less likely to report high levels of job autonomy and sufficient time to get their jobs done.

Job Displacement and Accession. The bi-annual Bureau of Labor Statistics survey used to establish the rate of job displacement does not include a measure of disability status. To provide a proxy measure of this phenomenon, I have analyzed the *Annual March Supplement to the Current Population Survey* in which respondents report their employment status for the year prior to the survey as well as for the prior week (Yelin, 1996). Among those who were employed in the year prior to the survey, persons with disabilities are more than three times as likely to report not being employed as of the week before the survey as those without disabilities (39.8 vs. 13.2 percent, respectively). Even after adjustment for health and functional status, demographic characteristics and the nature of the employment in the prior year, persons with disabilities who worked in the year prior to the survey are more than twice as likely to report not being employed as of the prior week as persons without disabilities (31.9 and 13.7 percent, respectively).

Among persons who reported no employment in the year prior to the interview survey, persons with disabilities were only a fifth as likely to be employed as of the week prior to interview as persons without disabilities (2.0 and 10.0 percent, respectively), and adjustment for health and functional status, demographic and prior work history did little to change this result (after adjustment, 2.1 and 9.4 percent of persons with and without disabilities who did not work in the year prior to the survey, respectively, reported that they were employed as of the week prior to the interview).

In a second set of analyses, I correlated the proportion of persons with disabilities employed in an industry in

each year with that industry's total share of employment in that year. The results suggest that persons with disabilities are more likely than persons without disabilities to be displaced from industries with a declining share of employment and more likely to obtain jobs in those gaining them (Yelin, 1992).

Finally, in the 1996 California survey described above, persons with disabilities did not report higher rates of job displacement, but they did report that when displacement occurred, it was more likely to result in a major problem in their lives.


Summary of Labor Market Dynamics

This review of overall trends in the labor market and of trends affecting persons with disabilities has yielded a partial description of how things are, not necessarily how they must be. Indeed, the evidence presented in this paper is consistent with the notion that, given the appropriate economic climate, a substantial number of persons with disabilities will enter the labor market and then maintain employment. Because a relatively small proportion of persons with disabilities do work and the exact proportion shifts with changes in the state of the labor market, there would appear to be a reasonable number who could work in the appropriate circumstances.

What is preventing them from doing so? Yelin and Trupin (1997) recently completed an analysis of the factors affecting transitions into and out of employment among persons with and without disabilities. For persons with disabilities, demographic characteristics were the principal factors affecting the probability of entering employment, with those 18 to 24 years of age six times more likely to do so than those 55 to 64 years of age and with whites 40 percent more likely to enter jobs as non-whites. Interestingly, the principal factor affecting whether persons with disabilities maintained employment was the in-

dustry in which they worked, while the principal factor affecting whether persons without disabilities did so was their occupation. This suggests that the probability that persons with disabilities will be able to keep working after onset of impairment is determined to a large extent by the welfare of the sectors in which they work, rather than their own characteristics. The welfare of persons without disabilities, in contrast, is tied to a greater extent to their personal background. Expanding industries will find a way to accommodate the needs of their workers with disabilities, level of impairment notwithstanding.

Thus, the question of how to assess the prospects for the employment of persons with disabilities in the years to come cannot be answered abstractly. Instead, it must be answered assuming a strong demand for labor. In addition, it must be asked assuming the presence of reasonable accommodation and strict enforcement of the anti-discrimination clauses of the Americans with Disabilities Act of 1990 (West, 1991). The lower rate of employment among persons with disabilities at each level of education suggests that such persons need the assistance of accommodation to take advantage of their training and experience on the one hand and, on the other, that employers may still not hire them, the presence of their training and experience notwithstanding.

Finally, it is difficult to predict the prospects for the employment of persons with disabilities because of the shifts in the kinds of work and in how work is done. Given the rising prevalence of disabilities associated with neurological impairments and mental conditions (Chirikos, 1993), there may continue to be a disjuncture between the functional capacity of persons with disabilities and the demands of jobs for the ability to communicate, concentrate, interact with others, and be flexible in how and when work gets done (Osterman, 1988). This is true even when a job demands the capacity for toting and lifting, but it is especially true in the growth sectors of the economy in which the physical demands of work may be minimal. 

Author's Note

1. Prior to 1970, published labor market series combined all non-Caucasians into one category. Accordingly, I am able to report racial differences in labor force participation from 1970 to 1996 only.

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Audio Cassettes of American Rehabilitation

Taped Copies of American Rehabilitation are available to blind and physically handicapped persons through local regional offices under the National Library Service for the Blind and Physically Handicapped. Contact your public library for the location of the regional library which serves your state.

Model Collaborative Career Program Established at the National Center on Deafness

A national model of career services for students who are deaf, hard of hearing and those with other disabilities has been established at the National Center on Deafness at California State University, Northridge. This multiproject collaborative effort will provide innovations that can be easily replicated at institutions and agencies throughout the country. In addition, each of the three allied projects will produce materials that are to be disseminated nationally for use by agencies, postsecondary institutions and employers.

For 30 years the National Center on Deafness (NCOD) at the university has been a leader in the exemplary services for students who are deaf and hard of hearing on a mainstream university campus. Once again, the NCOD has taken the lead in the establishment of a national model of career services known as the "NCOD Career WIT" program serving students who are deaf, hard of hearing and disabled. The program is a collaboration among three career projects, supported by federal and state funds, to establish services for the host campus and surrounding community, while implementing a program of national impact.

The three projects of the NCOD Career WIT program are:

- *WorkAbility IV (WAIV)*
- *Transition Resources and Career Services (TRACS)*
- *Increasing Career Choices for Individuals who are Deaf and Hard of Hearing (ICC)*

Functioning as a collaborative unit, Career WIT strengthens the type of programs and services that could be offered by each project individually. A "one-stop-shop" has been established that eases access for students, the campus community, area employers and service providers throughout the nation. It utilizes the unique talents of project staff to the mutual advantage of all programs. By working in concert, Career WIT is able to institute a broad network of campus and community contacts, enabling NCOD to serve a diverse base of constituents. The projects each build upon the resources of the other—for example, adding to the library of career-related materials—in effect tripling the capacity to provide optimal service to students and the community. Project staff work in unison to develop workshop curriculum, coordinate students and employers for

career fairs, share best practices and broaden program visibility.

While the one-stop-shop concept is not new in government and private services, the Career WIT program is the first of its kind for students who are deaf, hard of hearing and disabled at a mainstream university campus. Students who come to the NCOD Career WIT program have the advantage of the expertise and contacts developed by numerous program specialists for counseling and placement services. They also have a wider variety of career-related workshops tailored to meet their unique needs. The Career Center at the university and local employers also have more support and resources than ever before. Each campus career fair now has a place where students who are deaf can find sign language interpreters readily available, and students with other disabilities can find quick answers to their pressing questions or coaching on interviewing. Participating employers at the fairs find a visible presence where they can bring their questions, review material resources and explore the assistive technology display. For companies in the Greater Los Angeles area, large-scale training seminars on disability aware-

ness and the Americans with Disabilities Act are offered, with each Career WIT staff member speaking on their area of expertise. All constituents have the benefit of expanded online resources through the Career WIT Web site. The three projects that comprise Career WIT work in concert to offer top-quality services; however, each individual component has features that make it unique for the specific populations it serves.


NCOD's *WorkAbility IV* (WAIV) is the first hard of hearing/deaf-only project sponsored by the California State Department of Rehabilitation and, as such, the project has initiated many innovations. WAIV established a voice mail system for deaf students, allowing them the option of using a voice message service telephone number on their résumé. This service empowers students by giving them control over the timing of their disability disclosure. Knowing that individuals who are deaf prefer visual feedback, WAIV has established a mini-studio where students can participate in a videotaped mock interview that is used both to reinforce positive behaviors and to discuss negative ones. The WAIV Job Developer is also a sign language interpreter. This specialist accompanies students on interviews, meets employers face-to-face and provides direct feedback to students. Moreover, having an interpreter readily available for interviews reduces the stress on students to make interpreter requests to employers. A WAIV mentoring component, called "JOBNet," pairs current deaf and hard-of-hearing students with NCOD alumni working in fields students are considering. Other unique components are basic skills tutoring, helping students to develop the foundation they need to succeed in their major courses and a computer lab where students can build their computer proficiency as well as look for job vacancies, research companies and

develop their résumés. The services of WAIV have proven invaluable, however, as per contract the project can only work with students who are clients of the California State Department of Rehabilitation.

Transition Resources and Career Services (TRACS) is sponsored by a grant from the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS). TRACS is the only specialized program to offer unique individualized training and guidance for students who are disabled at California State University, Northridge. In addition, TRACS works across disabilities with high school and community college students, connecting them with other college and university students in a "Peer Sharing Network," to mentor and coach them with their college and other professional development pursuits. TRACS also offers training to high school teachers and counselors on career preparedness, to foster improved information to students with disabilities and encourage transition to higher education. Curriculum and handbooks for students and employers developed at Cal State Northridge by a previous grant are being updated and printed for national dissemination. An "Employer Accommodation Network" has been established, where area employers can connect with other area employers to discuss accommodation and other access issues, opening up more and more companies to hiring individuals with disabilities. TRACS has successfully placed students in jobs with companies like Disney, Allstate Insurance, Low Cost Insurance, and Future Scholars.

The newest addition to the NCOD career services is a project supported by a grant from the Rehabilitation Services Administration entitled *Increasing Career Choices for Individuals who are Deaf and Hard of Hearing* (ICC). ICC offers services to students who are deaf and hard

of hearing previously unable to take advantage of the tailored program offered by WAIV because they are not clients of the California Department of Rehabilitation. Through ICC, students receive services via direct communication in the mode most accessible to the individual—spoken English or sign language. ICC builds upon many innovations established by the WAIV program, such as the voice mail service and Job Developer/Sign Language Interpreter. In addition, through ICC, employers will be able to participate in an assistive device loan program, so they will not have this expense when taking on short-term interns. Furthermore, new hires can have equipment to use immediately while companies go through the process of purchasing their own equipment. The most unique product to be developed by ICC is a series of "Deaf Mentor" videotapes featuring deaf individuals from a variety of fields discussing their career paths and accommodations. An accommodation videotape will also be produced that will inform employers about accommodations and access issues for individuals who are deaf and hard of hearing, and instruct them on ways to acquire the technology and make their work environments "deaf-friendly."

The NCOD Career WIT program offers a tremendous range of programs, services, activities, and products to the Northridge community and to the nation at large. Each individual project offers specialties and builds upon the collaborative efforts of the other. Anyone wanting more information about any of these programs can contact the National Center on Deafness Special Projects office at (818) 677-2099. In addition to the products discussed, the Career WIT staff will document best practices as well those attempted that were not successful, and disseminate this information through state and national conferences, in publications and through direct contact. 



Juliette Rizzo (continued from contents page)

Ms. Rizzo received her bachelor's of science degree in journalism from Texas A&M University and her master's degree in journalism/public relations with a specialization in rehabilitation studies from the University of North Texas. Prior to coming to Washington, D.C., she was recognized with a "Best of Texas" award from the Texas Public Relations Association for work she produced as public relations director for Pierce, DeDittus and Galyean Advertising. She also served as Coordinator of Disability Support Services at Texas Woman's University, where she received numerous certificates of recognition from the Association on Higher Education and Disability (AHEAD) for creativity in the development of materials and events promoting academic support services for students with disabilities. On her own merit and with assistance from the vocational rehabilitation system and supportive employers, Ms. Rizzo has proven that a person with a disability can succeed when the appropriate supports are in place. With her strong background in media outreach, events planning and strategic communication targeted at raising awareness of issues of importance to persons with disabilities, their families and services providers, Ms. Rizzo directs a staff of seven professionals who support OSERS' Assistant Secretary and work with the Department to respond to public and press inquiries, write speeches and press releases, produce newsletters and Web sites, and plan OSERS' outreach events and activities.

NEW PUBLICATIONS AND FILMS

Study Guide to Essentials of Clinical Psychiatry. Based on the American Psychiatric Press Textbook of Psychiatry. Third Edition.

Donald M. Hilty, M.D., Robert E. Hales, M.D., M.B.A., and Stuart C. Yudofsky, M.D. American Psychiatric Press, 1400 K St., NW, Washington, DC 20005. Telephone: (202)682-6282. Softcover, 164 pages, \$30.00. ISBN: 0-88048-842-5.

Written principally to accompany *Essentials of Clinical Psychiatry*, this study guide may also be used with *The American Psychiatric Press Textbook of Psychiatry*, Third Edition, upon which *Essentials of Clinical Psychiatry* is based. Clinically focused, comprehensive, and up-to-date, *The American Psychiatric Press Textbook of Psychiatry* is a comprehensive reference book for the field of psychiatry.

This study guide provides readers of either the *Essentials of Clinical Psychiatry* or *The American Psychiatric Press Textbook of Psychiatry*, Third Edition, with an opportunity to evaluate their understanding of materials taken from sections on theoretical foundations, assessment issues, psychiatric disorders, psychiatric treatments, and special topics. It is an indispensable tool for medical students and residents in psychiatry, neurology and primary care, as well as psychiatrists and neurologists preparing for their specialty board examinations

Looking Within. How X-Ray, CT, MRI, Ultrasound, and Other Medical Images are Created and How They Help Physicians Save Lives.

Anthony Brinton Wolbarst. The University of California Press, 2120 Berkeley Way, Berkeley, CA 94720. Telephone: (510)643-0682. Softcover, 219 pages, \$19.95; hardcover, \$50.00. ISBN: 0-520-21182-0.

Looking Within explains in serious but nonspecialized language how X-ray, fluoroscopic CT, MRI, positron emission tomography (PET), ultrasound, and other medical pictures are created and it explores the essential roles they play in the diagnosis and treatment of patients. *Looking Within* should interest not only patients and their friends and loved ones, but also those who are simply curious about this vitally important, exciting and cutting-edge branch of medicine. The brief but clear descriptions of how these essential tools work should also be of value to healthcare providers in supporting and educating their patients.

3D Imaging in Medicine. Second Edition.

Jayaram K. Udupa and Gabor T. Herman, editors. CRC Press LLC, 2000 NW Corporate Blvd., Boca Raton, FL 33431. Telephone: (561)994-0555. Hardcover, 366 pages, \$129.95. ISBN: 0-8493-3179-X.

This volume provides a ready reference on the fundamental science of 3D imaging and its medical applications. It describes the principles and methods related to all aspects of 3D imaging, including image interpolation, filtering, segmentation, registration, isosurfacing, surface and volume rendering, quantitation, and evaluation of 3D imaging methods.

Policy, Program Evaluation, and Research in Disability: Community Support for All.

Julie Ann Racino. The Haworth Press, Inc., 10 Alice St., Binghamton, NY 13904-1580. 1-800-HAWORTH. Softcover, 475 pages, \$39.95, U.S.; \$48.00 outside U.S., Canada, and Mexico. Hardcover, \$69.95, U.S.; \$84.00 outside U.S., Canada, and Mexico. ISBN: 0-7890-0598-0.

Policy, Program Evaluation, and Research in Disability: Community Support for All is an essential research reference on how community support systems can greatly assist people with diverse disabilities to live fuller lives outside of institutions. Based on qualitative research methods, this book reflects over a decade of technical assistance and research in state, regional and local communities throughout the United States. Community service managers, policy-makers, researchers, activists, and individuals with disabilities and their families will benefit from the numerous

studies that promote a better quality of life for those living with disabilities.

What Psychotherapists Should Know About Disability.

Rhoda Olkin. The Guilford Press, 72 Spring St., New York, NY 10012. Telephone: 1-800-365-7006. Hardcover, 368 pages, \$35.00. ISBN: 1-57230-227-5.

This book should prove to be a valuable resource for mental health professionals. Blending her professional expertise with her personal experience as someone with a disability, the author presents a vivid account of the ways that living with a disability in today's society can affect daily life, the way one is perceived by (and relates to) others, and one's reasons for seeking therapy. Therapists will learn much more than how to determine if their offices are accessible—they learn to examine their own assumptions about disability, understand disability in the context of a specific person and conduct disability-affirmative assessment and treatment.

This book also contains much of value for members of the disability community. It provides a new understanding of disability as a social minority issue and elucidates the rights of persons with disabilities both in and outside of the therapy office.

An Intellectual Look at American Sign Language.

Tom Bertling, editor. Kodiak Media Group, P.O. Box 1029-K054, Wilsonville, OR 97070. FAX: (503)625-4087. Softcover, 112 pages, \$19.95 plus \$4.95 handling fee. ISBN: 0-9637813-7-5.

In addition to American Sign Language, the contributors to this book discuss deaf education, the importance of English reading and writing skills, deaf culture, ethical questions, Cochlear Implants, residential schools for the deaf, and the future for our deaf children. By venturing into the heart of deaf language and cultural issues, they reward us with critical thinking and skepticism largely absent from many of the proponents of ASL-based learning for deaf people. This is a powerful book for educators, administrators and

those working with individuals who are deaf.

Multiple Sclerosis: Your Legal Rights. Second Edition.

Lanny Perkins and Sara Perkins. Demos Medical Publishing, 386 Park Avenue South, Suite 201, New York, NY 10016. Telephone: 1-800-532-8663. Softcover, 224 pages, \$21.95. ISBN: 1-888799-31-5.

This extensively revised new edition provides a source of basic information about the legal problems that often affect people with MS and their possible solutions. These issues are addressed at a level understandable by a lay audience. The book will also be helpful to people in supporting fields such as social workers, healthcare professionals and attorneys.

Because of the variability of symptoms, both from person to person and over time within each patient, no one's experience is identical to that of anyone else. This presents special difficulties in planning for the future. Even so, there are important steps that everyone can take to help ensure that the hand of cards he/she is dealt is well played.

The authors make the case that the key to designing your future is educating yourself, thinking for yourself and acting in your own best interests. This book is meant to give you the tools to do exactly that.

Muscular Dystrophy in Children. A Guide for Families.

Irwin M. Siegel, M.D. Demos Medical Publishing, 386 Park Avenue South, Suite 201, New York, NY 10016. Telephone: 1-800-532-8663. Softcover, 130 pages, \$19.95. ISBN: 1-888799-33-1.

Written by a long-time muscular dystrophy (MD) specialist, this concise book guides families and older children through the often frightening labyrinth of medical care that one enters with a diagnosis of MD.

Patients will find honest, forthright discussion of such key issues as:

- The signs and symptoms of the disease and what they mean;
- All available treatment options;
- The probable course of the disease

and factors that may affect it; and

- Guidelines for current and future therapy.

Designed to inform and educate with state-of-the-art information, the book clearly defines available medical options at every stage of the disease and offers guidance even when it may seem that little or nothing can be done. It is essential for parents, families, older children with MD, teachers, friends, and indeed anyone affected by a diagnosis of muscular dystrophy.

Coping with Blindness: Personal Tales of Blindness Rehabilitation.

Alvin Roberts. Southern Illinois University Press, P.O. Box 3697, 1915 University Press Drive, Carbondale, IL 62902-3697. Telephone: (618)453-2281. Softcover, 144 pages, \$12.95. ISBN: 0-8093-2160-2.

The author tells stories drawn from the community of the blind and from his fellow rehabilitation workers to reassure others, especially the elderly—who are most at risk of becoming visually impaired—that “blindness need not be the end of active life, but rather the beginning of a life in which [people] will depend on their residual senses to continue full, active living.” Roberts’ personal experiences and conversations with colleagues have provided a wealth of incidents on which to base stories of rehabilitation workers with blind persons going about their daily tasks. He paints a positive picture of what it is like to be blind, replacing fear, dread and myth with reality.

Parkinson's Disease: A Self-Help Guide.

Marjau Jahanshahi, M.D., and C. David Marsden, M.D. Demos Medical Publishing, 386 Park Avenue South, Suite 201, New York, NY 10016. Telephone: 1-800-532-8663. Softcover, 381 pages, \$24.95. ISBN: 1-888799-38-2.

Parkinson's disease is one of the most common neurologic disorders. One person in every thousand of the population has it. Although young adults can develop the illness, it is usually a disorder of old age. In Western countries, increased life expectancy means that the proportion of elderly will also increase.

Since the risk of developing Parkinson's increases with age, there will be more people with it.

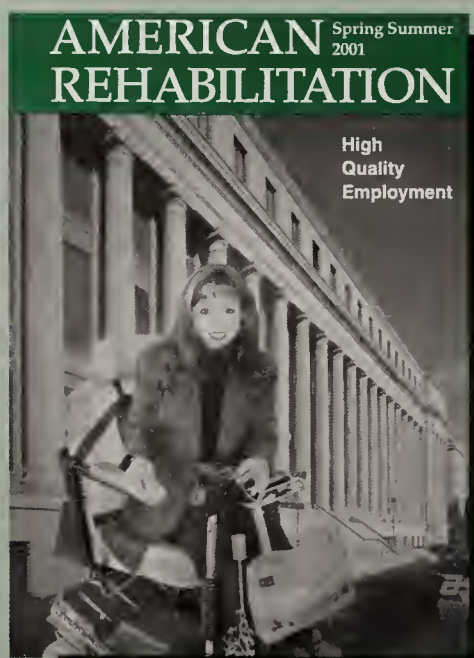
What is Parkinson's disease? What is the cause? Is there a cure? Can it be treated? What other symptoms will I get? How quickly will I deteriorate? Can I carry on working? Will it affect my mind? Will I need a wheelchair? Is there anything I can do to alleviate my symptoms? Will my children get Parkinson's disease? These are some of the questions that will be asked by someone who has been diagnosed as having Parkinson's disease. In the limited time available in an initial visit, most doctors can provide only minimal information about the nature of the disorder and its drug treatment. Some of these questions may not come to mind when a person is first told that he or she has Parkinson's disease. It is usually during the following days and weeks that some of the questions will surface. The subsequent medical management of the illness mainly focuses on adjusting the level of medication to control the symptoms. The person with Parkinson's disease and his or her family are often left unaided to anticipate and adapt to the long-term social implications. The aim of this book is to fill this gap in patient-doctor communication and to provide the individual

and his or her family with the essential information about the nature of the illness, its diagnosis and medical treatment, its implication for their daily lives, and about how best to cope with the changes brought about by it.

The book is organized into three main parts. The first, "Parkinson's Disease: The Medical Facts," provides up-to-date medical information about the symptoms, what is known about the possible causes, the aims and procedures of different tests used in diagnosis, and treatment with medication or surgery. In this era of modern health-care, the individual is considered an active participant in his or her health-care rather than a passive recipient of treatment. "Patient education"--or providing the person with a chronic illness with information about the disorder and its medical treatment--is beneficial in two main ways. First, it can alleviate the anxiety and anticipation experienced when an individual faces the unknown. By creating a sense of familiarity, information can generate a sense of choice and control. Second, it provides the individual with the opportunity to actively participate in his or her own healthcare. The person diagnosed with Parkinson's disease has to travel many novel and personally uncharted waters in the course of the illness. The general medical informa-

tion provided in Part I may provide signposts to guide the person with Parkinson's disease and his or her family on this journey. Informed decisions are often more rational, and their consequences easier to live with, and it is hoped that the information provided in Part I will facilitate such informed decisions.

The onset and development of a progressive and disabling illness such as Parkinson's constitute a traumatic life crisis that can have a major impact on the psychological well-being and social functioning of both the person with the disorder and his or her family. The knowledge that one's experiences are not unique, that they are shared by others in the same situation, can be reassuring and take the edge off the threatening aspects. The experience of Parkinson's disease is shared by approximately 500,000 people in the United States. As the great variability of symptoms across individuals would imply, there is no one form of the disorder. This, combined with the very individual way in which each person responds to stress and change means that no standard experience of the illness exists either. Nevertheless, by portraying some of the common experiences of living with it, this book intends to offer some assurance to those who have to experience it.



If you find in *American Rehabilitation* the kind of material that informs or that is useful to you in some way, a colleague who does not receive the magazine may also profit by it. If you know such a person, fill out the blank below and send it to Editor, *American Rehabilitation*, Room 3033, 330 C Street, S.W., Washington, DC 20202-2531. We will be happy to send your friend a sample copy of the magazine.

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Symptom Management in Multiple Sclerosis. 3rd Edition.

Randall T. Schapiro, M.D. *Demos Vermande*, 386 Park Avenue South, Suite 201, New York, NY 10016. Toll-Free Telephone: 1-800-532-8663. Softcover, 204 pages, \$19.95 plus \$4.00 for shipping and handling.

Management strategies for multiple sclerosis fall into two general categories—those used to treat the underlying disease process and those used to minimize and control specific symptoms such as spasticity, bowel or bladder problems, or fatigue. This volume focuses on the management of specific symptoms that may develop as the result of the disease process in multiple sclerosis. It is based on the management program developed at The Fairview Multiple Sclerosis Center in Minneapolis.

Wheelchair Selection and Configuration.

Rory A. Cooper, Ph.D. *Demos Medical Publishing, Inc.*, 386 Park Avenue South, Suite 201, New York, NY 10016. Telephone: (212) 683-0072. Softcover, 424 pages, \$34.95.

A definitive text for everyone concerned with wheelchair selection, including physical and occupational therapists and other healthcare providers involved with helping patients to achieve optimal seating. Chapters discuss wheelchair measurement, engineering fundamentals, biomechanics, electronics, and standards. Various types of wheelchairs are considered, including manual, powered, specialized, and sports chairs; the selection of seat cushions and specialized seating systems are considered in depth and assessment and intervention are reviewed.

The Complete Learning Disabilities Directory. 6th Edition.

Grey House Publishing, Pocket Knife Square, Lakeville, CT 06039. Toll-Free Telephone: 1-800-562-2139. Softcover, 642 pages, \$130.00 plus \$10.00 shipping and handling.

This sixth edition now has over 6,500 entries, detailing LD associations and organizations; schools, colleges, and learning centers; assistive devices and computers; books, tapes, and periodicals; government agencies; and camps and summer programs. With a wealth of information not found in previous editions, this directory may be the most comprehensive resource for individuals with learning disabilities. The Entry and Subject Indexes have been completely updated and a new Geographic Index has been added.

Spinal Cord Injury: An Analysis of Medical and Social Costs.

Monroe, Berkowitz, Paul K. O'Leary, Douglas L. Kruse, and Carol Harvey. *Demos Medical Publishing, Inc.*, 386 Park Avenue South, Suite 201, New York, NY 10016. Telephone: (212) 683-0072. Hardcover, 208 pages, \$89.95.

This volume expands and updates information previously presented in *The Economic Consequences of Traumatic Spinal Cord Injury* and reports results from a new survey of the costs of spinal cord injury (SCI). It explores the elements that make up both the medical and nonmedical direct costs of SCI, focusing specifically on the costs of home modifications, vehicle adaptations, and wheelchairs. It also focuses on the determinants of employment for persons with SCI.

Coping with Blindness. Personal Tale of Blindness Rehabilitation.

Alvin Roberts. *Southern Illinois University Press*, P.O. Box 3697, Carbondale, IL 62901. Telephone: (618) 453-6633. Softcover, 123 pages, \$12.95.

Sightless himself and a veteran of four decades of helping people cope with blindness, Alvin Roberts decided that telling stories drawn from the community of the blind and from his fellow rehabilitation workers was the best way to reassure others—especially the elderly, who are most at risk of becoming visually impaired—that “blindness need not be the end of active life, but rather the beginning of a life in which

[people] will depend on their residual senses to continue full active living.”

As the reader soon learns, Roberts is a skilled raconteur. Very skilled. He arms himself with the full arsenal of the storyteller's tricks—drama, irony, action, traces of tall tale, and humor—especially humor. He tells unsentimental stories about how blind people face their affliction and eventually cope with it. The stories are based on the author's experience, that of people he has met and worked with, and that of his coworkers.

Roberts shows that there is competent help for visually impaired persons. And he shows that there is hope for a full life. He paints a positive picture of what it is like to be blind, replacing fear, dread, and myth with reality.

Alvin Roberts is the regional administrator for the Bureau of Blind Services in Carbondale, Illinois. He has more than 40 years experience as a rehabilitation teacher of the blind. He is the author of *Psychological Rehabilitation of the Blind* and a book of short stories, *Tavern Tales*.

New Frontiers in Psychosocial Occupational Therapy.

Anne Hiller Scott, editor. *The Haworth Press, Inc.*, 10 Alice St., Binghamton, New York, NY 13904-1580. Toll-Free Telephone: 1-800-429-6784. E-mail: <getinfo@haworthpressinc.com> Hardcover, 176 pages, \$29.95.

Articles in this publication explore plans and processes to improve patient care through enhanced therapist/patient relationships and strong alliances with mental health advocate groups. In addition to articles written by therapists, patients, and occupational therapy educators, this text features several students' personal accounts of their fieldwork experiences and how they overcame the fear of inadequacy, learned additional procedural skills in occupational therapy assessment, became comfortable with group leadership, and, as a result, learned the importance of patient/practitioner relationships as they relate to improved services.

**Winnie Tunison
cannot see or hear you.**



**But she sure can
feel you make a difference.**

While people who are deaf-blind have benefited greatly from the programs of the Helen Keller National Center and technological advances, they still need your help and personal support in order to succeed.

Born deaf, Winnie began to lose her vision at age 31. With the support of her husband, two daughters, teachers, and peers at Helen Keller, she gained new skills and went on to graduate with honors from Gallaudet University. Like Winnie, who now works as a teacher and ceramicist, other people who are deaf-blind can lead independent and fulfilling lives. As an employer, neighbor, classmate, or friend, **YOU CAN MAKE A DIFFERENCE.** Call 1-800-255-0411, x270 for information.

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A Reflection on the Vocational Rehabilitation Program

Continued from the inside front cover

The Role of Adult Basic Education Programs

Recognizing what the *Longitudinal Study* indicates about the importance of basic skills in reading and math to consumer earnings and the availability of health insurance benefits, clearly basic skills training for our consumers is an area that requires our attention, if we are truly committed to reaching beyond a quantitative outcome focus. It is time for us to begin, in earnest, partnerships with adult basic education programs. These partnerships could enable both VR agencies and adult basic education programs to improve products and services. For adult basic education programs, the "plus side" is an improvement to their programming for individuals with learning and other disabilities. Adult basic education programs are already serving these populations through their work with transitioning welfare recipients and others. For VR, there is the benefit of not having to reinvent basic skills training and to utilize existing structures.

Effective Service to Individuals with Disabilities Within Adult Basic Education Programs

In building partnerships with adult basic education programs, certain factors need to be taken into account to increase the likelihood of success among VR consumers accessing these services. Adult basic education is not viewed by most VR counselors as beneficial for individuals with mental retardation and other cognitive disabilities. How-

ever, there is a greater potential for skill improvement if the skills training is provided in relationship to the job functions being completed by such an individual. If VR counselors had an understanding of adult basic education programs and the kinds of services they provided and could explain them, more consumers might pursue this option in their search for quality employment.

In general, adult basic education programs are not designed with individuals with disabilities in mind. There are several ways that this barrier can be overcome. On the accommodation side, there needs to be physically accessible teaching space, alternate format materials and interpreter services available, specialized diagnostic and assessment capabilities, and a recognition of differing learning and test-taking styles, among other accommodations.


In terms of programmatic understanding and incorporation of basic approaches to serving individuals with disabilities, the following characteristics appear necessary within adult basic education programs in order to facilitate success of VR consumers and other individuals with disabilities:

- Association of the material learned to the functions completed in the work setting;
- Building on the student's existing knowledge base, rather than approaching learning from a remedial perspective;
- Fostering the student's self-esteem and giving regular and frequent feedback;

- Providing assistance in realistic goal-setting; and
- Accepting differing learning and test-taking styles.

The Future of VR/Adult Basic Education Partnerships

Much needs to be done to educate and inform professionals in both the VR and adult basic education fields regarding the participation of individuals with disabilities in skill development programs. The results of the *RSA Longitudinal Study* lay out for us in no uncertain terms that there is a link between skill levels in reading and math and an individual's earning capacity. We can no longer afford to ignore what we have so long suspected.

If VR approaches the adult basic education community with a message that this can be a "win-win" partnership, wherein the expertise of VR professionals augments the efforts of adult basic education programs to serve all individuals with disabilities, it seems highly likely that we can build a meaningful and mutually beneficial relationship between the two programs at each state and local level. VR professionals can expect technical assistance materials from RSA regarding adult basic education programs, how to contact them and how to partner with them more effectively. In addition, RSA and our other federal partners within the adult basic education community will work to develop demonstration and other projects to encourage innovation in this area. 

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